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# Experiences of people with Parkinson's disease and their views of physical activity interventions: a qualitative systematic review

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# Experiences of people with Parkinson's disease and their views of physical activity interventions: a qualitative systematic review.

## Abstract

**Objective:** To synthesize the best available qualitative evidence of people with Parkinson's disease experiences and preferences for physical activity, their perceived motivators and barriers to engagement, as well as people with Parkinson's disease views of support mechanism and behavior change interventions designed to sustain participation.

**Introduction:** National and international guidelines recommend regular physical activity to improve health and wellbeing and to prevent disease. Research in Parkinson's disease indicates that physical activity programs can be beneficial in addressing both physical symptoms and overall wellbeing. However, despite recommendations, sustained engagement in regular physical activity is limited. To promote physical activity it is important to understand the perspectives of people with Parkinson's disease relating to this topic.

**Inclusion criteria:** This review considered studies that included a qualitative evaluation of the experiences and views of people with Parkinson's disease towards physical activity and interventions designed to sustain participation.

**Methods:** The databases (MEDLINE, EMBASE, CINAHL, AMED, SCOPUS and Web of Science), and unpublished studies in sources of grey literature (Google, Open Grey, MedNar, Conference Paper Index, PQDT) were searched. Language limiters were restricted to English language and dates ranges from the inception of the database until 30 June 2017. Two reviewers assessed studies that met the inclusion criteria independently, using the criteria of the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research. One reviewer, completed data extraction using the standardized qualitative data extraction tool. This was checked for accuracy, by a second reviewer. The qualitative research findings were pooled using the JBI methodology. The JBI process of meta-aggregation was used to identify categories and synthesized findings.

**Results:** Nineteen studies were included in this review following consideration of the methodological quality of each study. Two studies were excluded after the methodological review, as the findings were not supported by illustrations of the participant voice. Subsequently 105 findings were extracted and aggregated into 20 categories and eight synthesized findings. Methodological quality was variable and overall confidence in the findings was determined to be low.

**Conclusion:** This review revealed that people with Parkinson's disease viewed physical activity as an enjoyable and positive experience, which aided with control of their symptoms and enhanced their wellbeing and quality of life. In agreement with the evidence from older adults and those with long-term conditions, this review identified disease presentation, intrapersonal characteristics, program design, external support and the social and physical environment, as contributory factors, which influenced people with Parkinson's disease's ability to sustain engagement in physical activity. The unique contribution and weighting of these factors will affect an individual's participation in physical

activity. This review gave an important insight into the challenges of undertaking physical activity while living with a progressive and fluctuating disease. These qualitative findings give health care providers an insight into the views and experiences of people with Parkinson's disease and are useful, alongside quantitative evidence of effectiveness, for the design of physical activity programs that are meaningful for people with Parkinson's disease. However, a limitation of this review is that it does not address the views and experience of people with Parkinson's disease who are inactive.

**Keywords:** Experiences; Parkinson's disease; Participation; Physical Activity; Qualitative

## Summary of Findings

The ConQual approach<sup>1</sup> was used to assess and report confidence in the results of this qualitative systematic review. The 19 papers included in this review were all qualitative studies and were assessed for dependability based upon the number of 'yes' answers on the dependability score, with high grade awarded to studies that had four to five yes scores, moderate grade to those with two to three 'yes' scores and a low grade for a zero to one 'yes' score. See appendix 1a for Dependability score for each qualitative research paper. Credibility of the findings was graded at three levels: those that could not be challenged were graded unequivocal (U), those that could be challenged were graded credible (C) and those that were not supported (Ns). Only those findings graded as unequivocal or credible were extracted for data synthesis. (See Appendix 1b for development of ConQual Score). The level of credibility of each finding was based on consensus between two reviewers.

<b>Systematic review title:</b> Experiences of people with Parkinson's disease and their views of physical activity interventions: a qualitative systematic review. <b>Population:</b> People with a diagnosis of Parkinson's disease <b>Phenomena of interest:</b> The experiences, preferences, barriers and enablers to physical activity, and the use of behavioral interventions and support strategies to sustain participation. <b>Context:</b> People with Parkinson's disease who live in a community setting.					
Synthesized finding	Type of research	Dependability	Credibility	Final ConQual score	Comments
<b>Participating in physical activity is seen as positive</b> , with participants reporting improvements in physical and psychological function and symptom control. Participating in physical activity led to holistic changes, including a sense of achievement, improved confidence and wellbeing	Qualitative	Downgraded 1 level	Downgraded 1 level	<b>Low</b>	Downgraded 2 levels due to moderate dependability and moderate credibility
<b>Parkinson's disease is perceived to impact on all aspects of physical activity</b> with temporal	Qualitative	Downgraded 1 level	Downgraded 1 level	<b>Low</b>	Downgraded 2 levels due to moderate dependability

fluctuation in symptoms presenting both emotional and physical challenges. Changes to the level and type of physical activity and the use of individual strategies is used to maximize participation.					and moderate credibility
<b>Participation in physical activity is highly individual</b> , with participants valuing activities which are perceived as personally relevant and tailored to their needs and preferences. Participant perceptions of physical activity are affected by expectations and self-evaluation of progress.	Qualitative	Downgraded 1 level	Downgraded 1 level	<b>Low</b>	Downgraded 2 levels due to moderate dependability and moderate credibility
<b>External factors can affect participants' experience of physical activity.</b> Involvement of family members/ friends and use of music make session's enjoyable and increase wellbeing. Support from instructors to ensure physical activity programs are structured and simple to undertake, to explain the relevance of activities and to support progression gives participants' confidence and enhances their participation	Qualitative	Downgraded 1 level	Downgraded 1 level	<b>Low</b>	Downgraded 2 levels due to moderate dependability and moderate credibility
<b>A personal desire to maintain independence and a belief that physical activity can slow deterioration are driving forces for participation.</b> Motivation is enhanced by perceived improvement in symptoms and feelings of accountability to oneself or others.	Qualitative	Downgraded 1 level	Downgraded 1 level	<b>Low</b>	Downgraded 2 levels due to moderate dependability and moderate credibility
<b>Participants report that personal characteristics such as exercise habit, information seeking, resilience, problem solving and interest in the activity are motivators for engagement.</b> However,	Qualitative	Downgraded 1 level	Downgraded 1 level	<b>Low</b>	Downgraded 2 levels due to moderate dependability and moderate credibility

lack of time, low outcomes expectations and cultural challenges are seen as barriers. Comparisons with others can be a motivator or barrier to engagement					
<b>Difficulty obtaining an initial diagnosis, accessibility of services, disease symptoms (both physical and psychological) and severity all impact on people with Parkinson's disease's ability and desire to undertake physical activity.</b>	Qualitative	Downgraded 1 level	Downgraded 1 level	<b>Low</b>	Downgraded 2 levels due to moderate dependability and moderate credibility
<b>Participants report group members, family, friends, and co-workers provide support for them to initiate and sustain physical activity.</b>	Qualitative	Downgraded 1 level	Downgraded 1 level	<b>Low</b>	Downgraded 2 levels due to moderate dependability and moderate credibility

## Background

Parkinson's disease (PD) is the second most common neurodegenerative disease after Alzheimer's,<sup>2</sup> with incidence increasing with age; affecting 1% of the industrial countries population over 60 years and 4% over 80 years.<sup>3</sup> Parkinson's disease is associated with abnormal neuronal activity in the basal ganglia due to the loss of dopaminergic neurons in the substantia nigra.<sup>4</sup> This produces the cardinal features of PD; difficulty in initiating movements (akinesia) as well as slowness and difficulty maintaining movement (bradykinesia), tremor and rigidity.<sup>5</sup> At onset, symptoms are normally unilateral but as the disease progresses bilateral symptoms present with significant disability. Non motor symptoms include fatigue,<sup>6</sup> anxiety and depression.<sup>7</sup> Despite optimal medical management, the progressive nature of the disease often results in people with Parkinson's disease (pwPD) experiencing reduced function and mobility.<sup>8</sup> Consequently, pwPD tend to adopt a sedentary lifestyle and demonstrate lower levels of physical activity (PA) than healthy peers.<sup>9,10</sup> For example, a large study which compared the PA data of pwPD (n=699) to controls (n= 1,959) found that pwPD were, on average 29% less active compared to age matched controls.<sup>9</sup> Furthermore, Lana et al found increased age, disease severity and inability to perform activities of daily living to be predictors of physical inactivity in pwPD.<sup>11</sup>

Physical activity is defined as "any bodily movement produced by skeletal muscles that results in the expenditure of energy".<sup>12(p127)</sup> This is an umbrella term for the sum of all activity undertaken throughout the day and can be subdivided into:

- Leisure time physical activity (e.g. walking and swimming);
- Non-leisure physical activity (occupational and household), and
- Exercise (e.g. aerobic, strengthening, flexibility), which is structured and repetitive and is specifically aimed to improve or maintain physical fitness.<sup>12</sup>

There is substantial evidence to support the benefits of a range of interventions designed to reverse the sequelae of physical inactivity in pwPD.<sup>13-18</sup> To date, programs have tended to be supervised exercise programs in institutional settings and have reported improvements in quality of life, improved ambulation, balance, strength, flexibility and cardiovascular fitness compared with those who did not exercise.<sup>13,14,16</sup> A criticism of much of this research is that the interventions are time limited and highly supervised with follow-up limited to short term (3-6 months). Therefore, it is difficult to determine if PA is sustained long term following an intervention. Results from research across a variety of populations,<sup>19-21</sup> suggests that a return to physical inactivity upon cessation of such interventions is a reality. This is likely to be the case for pwPD unless strategies for the maintenance of long-term participation are developed.

More recently, an alternative approach to encourage sustained participation in PA is the use of 'leisure-based' activities such as Tai Chi and dance, both of which have demonstrated improvements in balance and mobility.<sup>22-24</sup> In a study which compared Tai Chi to a progressive resistance training program, at follow up (three months later) pwPD who undertook Tai Chi had improved perceptions of health related benefits and showed greater probability of continued exercise behavior than the resistance-training group.<sup>25</sup> "Dance for Parkinson's" groups view dance as being an alternative form of PA with an emphasis on the creative, social and artistic practice that may also help alleviate

symptoms and improve quality of life.<sup>26</sup> However, long-term studies that measure sustained participation are lacking and the cost of attending dance classes identified as a barrier.<sup>27</sup> Because PA activity is a complex and dynamic process involving an intricate series of behaviors, identification of the variables affecting uptake and sustained participation is difficult.<sup>28</sup> Therefore, the views of pwPD concerning their preferences as well as motivators and barriers to PA would be helpful to ensure that programs meet the needs of the intended audience. Personal characteristics of pwPD have been shown to influence motivation to undertake PA. Research in pwPD identified the importance of self-efficacy, education and age as significant factors associated with increased PA.<sup>29</sup> Enabling factors which have been identified in the PD literature include provision of peer and/or family support via instrumental, (e.g., provision of transport and mutual participation), emotional (e.g., provision of encouragement through a variety of face-to-face and remote means), and informational mechanisms, (e.g., type of exercise that would be beneficial to their condition by health professional or fitness instructor).<sup>30</sup>

Changing health behavior in terms of moving from a sedentary lifestyle to one that is physically active is both a complex and challenging process, particularly as the success of many rehabilitation programs requires both attendance at structured sessions and adherence to unsupervised home-based exercises.<sup>31</sup> Simply informing people about the benefits of PA has been shown to be inadequate in sustaining behavioral change,<sup>31,32</sup> leading to the development of behavioral change interventions in a number of long-term conditions. Studies evaluating their effectiveness have shown mixed results,<sup>20,33,34</sup> highlighting the need to develop an understanding of service users' experiences and perceptions of these interventions in order to inform which specific aspects should be incorporated into PD specific programs.

In the context of this systematic review, behavior change interventions' were defined as any psychology-based interventions (used alone or in combination with other interventions, such as exercise therapy) aimed directly or indirectly at behavior change with regard to level of PA participation or change in perceived physical function. Such interventions include goal setting, cognitive re-structuring, and motivational interviewing.<sup>31</sup>

In order to facilitate behavioral change in pwPD they might need disease-specific coaching and counselling.<sup>35</sup> The effect of the addition of behavior change interventions (goal setting, coaching and use of activity monitor to provide feedback) was studied in a multi-faceted PA program in pwPD over a two-year period.<sup>36</sup> Results identified increased PA in almost all sub groups of pwPD (grouped by gender, activity level and disease severity),<sup>36</sup> however, the overall time spent on physical activities (primary outcome measure) did not change.<sup>37</sup> Thereby illustrating the challenges of facilitating behavior change in pwPD. The effect of a daily interaction with a virtual exercise coach (5mins a day) to encourage an increase in walking (measured by a pedometer) was studied in pwPD. Coaching included discussing progress with short and long-term goals and positive reinforcement with joint problem solving to overcome barriers. Results after one-month demonstrated an excellent retention rate with the walking program and improvements in objective measures of gait.<sup>38</sup> However, the main limitation was that the trial only lasted for one month and it is unknown whether pwPD would maintain their walking program long term and whether behavior change had occurred. The mixed results

illustrate the challenges for changing health behavior in pwPD.

In summary, this systematic review considered pwPD experiences and preferences for PA, their perceived motivators and barriers to engagement as well as pwPD views of support mechanisms and behavioral change interventions designed to sustain participation.

The Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports, the Cochrane Library, PROSPERO, CINAHL, and Medline databases were searched to identify if a systematic review on this theme has previously been conducted or was in progress. None was found.

## **Objectives**

The purpose of this qualitative systematic review was to synthesize the best available evidence of pwPD experiences and preferences for PA, their perceived enablers and barriers to engagement, as well as pwPD views of support mechanism and behavior change interventions designed to sustain participation.

The objectives were to

Explore pwPD experiences of and preference(s) for physical activity

Explore pwPD perceptions of barriers and enablers to physical activity

Identify, from the perspective of pwPD, the impact of support mechanisms and behavior change interventions in maintaining participation in physical activity.

## **Inclusion criteria: Participants**

The review considered studies that included pwPD with a confirmed diagnosis.

## **Phenomena of interest**

The review considered studies that explored experiences, preferences, barriers and enablers to PA in pwPD, including the use of behavioral interventions and support strategies.

## **Context**

The context was any community setting where pwPD live.

## **Types of Studies**

Studies considered for this review were those in which qualitative data had been obtained and analyzed on the proposed phenomena of interest. Studies of interest included methodologies and approaches such as qualitative design, phenomenology, grounded theory, ethnography, action research and the qualitative aspect of mixed methods. There was no age limit applied to the studies considered for Inclusion.

## **Method**

This qualitative systematic review utilized meta-aggregation to synthesize the best available evidence following the published *a priori* protocol<sup>39</sup> registered with PROSPERO (CRD42017084025)

## **Search Strategy**

A three-step search strategy was utilized to find published and unpublished studies. Firstly, an initial limited search of MEDLINE was undertaken using preliminary key words. Analysis of the text words



contained in the title and abstract, and index terms used to describe the article were utilized to identify key words that were more relevant. Based on this, the search strategy was developed and refined through discussion with the research team and an information specialist. (See Appendix II for search strategies)

Subsequently, the final search strategy was applied to the following databases: MEDLINE (via OVID), EMBASE (via OVID), CINAHL (via EBSCO), AMED (via EBSCO), SCOPUS and Web of Science. The latter two include both published and unpublished studies. For some databases such as SCOPUS and Web of Science the search strategy had to be modified. Each electronic database was searched from the inception of the database until 30 June 2017 to provide the most comprehensive synthesis possible. Only studies published in English were considered for inclusion. The search for unpublished studies also included: PQDT, Conference Paper Index, OpenGrey, MedNar and Google. The CRO database was not searched (a deviation from the published *a priori* protocol) as it could no longer be found

Lastly, a hand search of the reference list of included studies was undertaken to determine if there were any other studies for inclusion.

### **Study selection**

Records of references were collated with the use of Endnote VX8 (Clarivate Analytics, PA, USA) and duplicates removed prior to screening. Two reviewers scanned all titles and abstracts to exclude papers that clearly did not align with the inclusion criteria, for example not Parkinson's disease or not relating to PA. Full text articles were obtained for papers that met the inclusion criteria or where there was uncertainty, which were then independently assessed against the inclusion criteria by two reviewers. Any disagreements were resolved via discussion, and where needed, a third reviewer consulted. The eligible studies selected through this process were then imported into Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information (JBI SUMARI).

### **Assessment of methodological quality**

Eligible studies were appraised for methodological quality using the JBI Critical Appraisal Checklist for Qualitative Research.<sup>40</sup> The checklist consists of 10 criteria concerning the methodology, methods and findings of qualitative studies. Three members of the review team participated in this step, and each paper was appraised independently by two of them. Discrepancies that arose between the reviewers were resolved through discussion. No studies were excluded based on methodological quality

### **Data Extraction**

Qualitative data were extracted using the JBI Qualitative Data Extraction Tool.<sup>40</sup> The primary reviewer initially performed data extraction for each study independently, which was subsequently checked for

accuracy by a second reviewer. Firstly, following repeated reading of the studies, the findings plus their accompanying illustrations, were extracted. A finding is defined by the JBI as “a verbatim extract of the authors’ analytic interpretation accompanied by either a participant voice, or fieldwork observations or other data”.<sup>40(p40)</sup> Findings were extracted from either the theme or sub theme level depending on whether they were accompanied by an illustrative quotation directly attributed to a pwPD, and which were related to the objectives of the review. During data extraction, a decision was taken to exclude two studies<sup>41,42</sup> from extraction and further analyses as the findings of these studies were unsupported by any illustrations of the participant voice. Therefore, only 19 studies were utilized for the synthesis

The data extracted included specific details about methodology, method, phenomena of interest, setting, geographical location, cultural context, participants, data analysis and the study author’s conclusions and reviewer’s notes.

### **Data Synthesis**

The qualitative research findings from the included studies were synthesized following the JBI meta-aggregative approach.<sup>40</sup> Firstly, the primary reviewer and secondary reviewer rated each extracted finding independently according to the three levels of credibility, (unequivocal, credible or unsupported):

- Unequivocal –findings with illustrations beyond reasonable doubt and, thus not open to challenge.
- Credible –findings with illustration that are plausible and inferred from the data, but open to challenge.
- Unsupported –findings not supported by the data.<sup>1</sup>

Consensus was agreed via discussion and where there was more than one quotation, for a finding, the highest level of credibility among the quotations was assigned. Findings considered unsupported (i.e. no participant quote provided) were eliminated from further analysis.

Subsequently, the findings deemed unequivocal or credible were grouped into categories by the primary reviewer based on similarity of meaning and then discussed with the secondary reviewer until agreement was reached. The categories were then examined by the primary reviewer, and those with commonality were aggregated to form synthesized statements which represented conclusions based on the findings from the included studies and could form the basis for recommendation for practice and policy. The synthesized findings were reviewed and refined by all reviewers, to ensure consensus.

### **Confidence in the synthesized findings**

A ConQual score was generated for each synthesized finding to provide a level of confidence in the evidence.<sup>1</sup> The level of confidence for each synthesized finding is scored as high, moderate, low or very low based on the dependability of the primary studies and the credibility of their research findings. The ConQual score is downgraded in consecutive order, from a starting point of high, on the

basis of summing the scores applied to dependability and credibility ratings.

Dependability was derived from answers to the five criteria on the JBI Critical Appraisal Checklist for Qualitative Research. The dependability score was then applied to the research findings from that study whereby a level of high was given to those studies, which met four or more of the criteria, medium to those that met two or more of the criteria, and low to those studies that were only able to satisfy one or more of the criteria. Subsequently, the dependability of the synthesized finding was derived from the balance of the aggregated level of the dependability scores from across the included studies. Findings that had greater than 50% of included studies rated either high or moderate were assigned a moderate level of dependability.

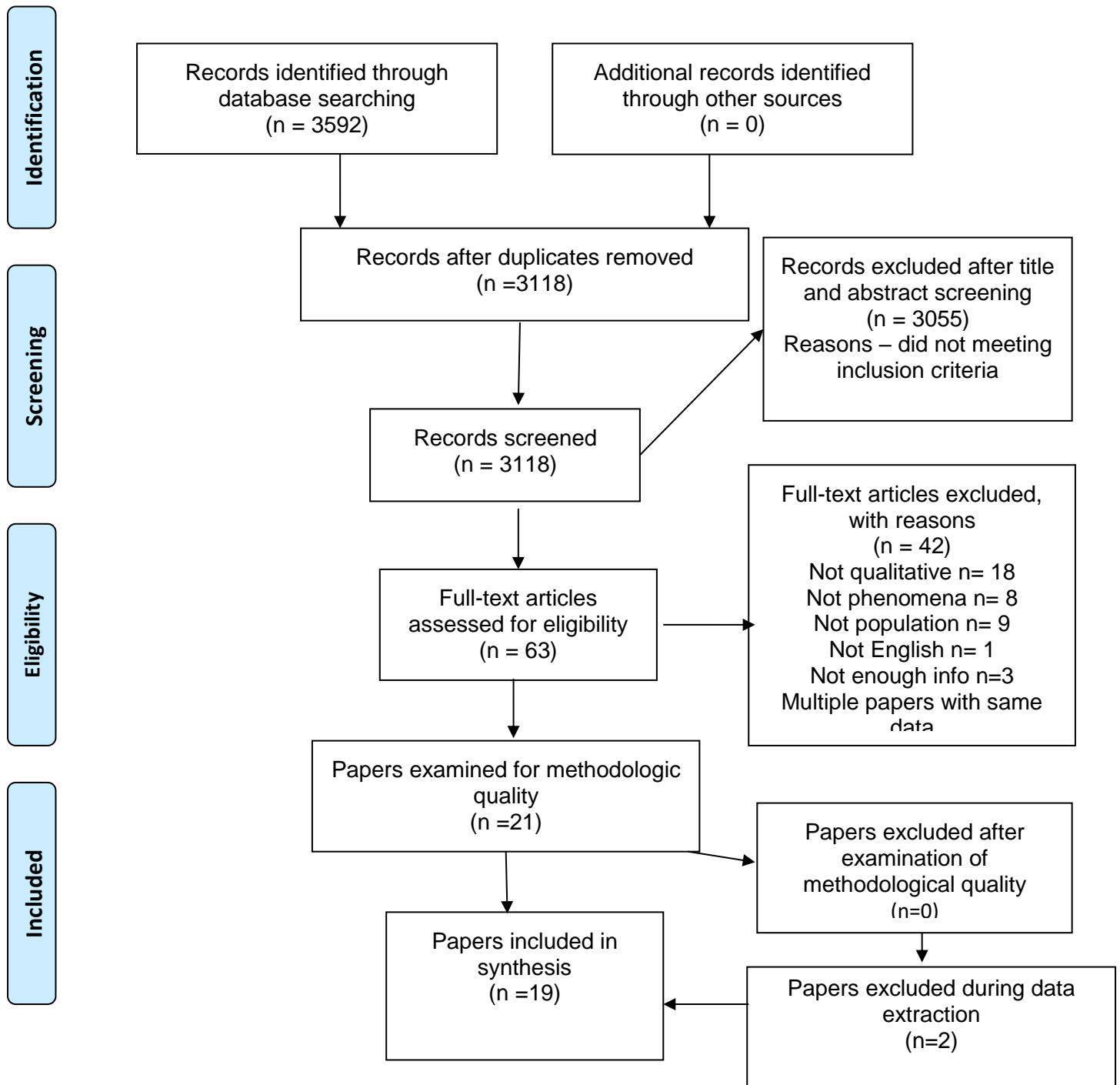
Credibility of each research finding was established by determining the congruency between the study author's interpretation and the illustration (participant voice) and could be either unequivocal or credible.<sup>1</sup> The credibility of the synthesized finding was determined by the balance of unequivocal and credible findings: if the finding only included unequivocal findings it was graded as high, a mixture of unequivocal and credible as moderate, inclusion of only credible as low. See appendix Ia and Ib for details of dependability and credibility scoring for this systematic review.

## **Results**

### **Study inclusion.**

The search produced a total of 3592 results, which reduced to 3118 after de-duplication. Screening identified 63 studies, deemed relevant to the objectives of the systematic review based on the assessment of the titles and abstracts. The full text of these papers was retrieved for review, following which 42 papers were excluded, based on not meeting the inclusion criteria. See figure 1 for the search results via the PRISMA flow diagram.<sup>43</sup> See Appendix III for excluded studies with reasons. The remaining 21 papers were examined for methodological quality. No studies were excluded due to methodological quality. However, during data extraction, two studies<sup>41,42</sup> were excluded from further data synthesis, as findings were not supported by an illustrative quote. The exclusion of unsupported findings from the synthesis will enhance the credibility score of the findings. Characteristics of 19 included studies are presented in Appendix IV.

**Figure 1: Flowchart of study selection process**



### Methodological quality

The methodological assessment of the studies is presented in Table 1. There was a range of methodological quality among the 21 studies. Their quality ranged from high to low: 16 studies achieved appraisal scores of 70% or more, indicating that at least seven or more of the 10 assessment criteria were met. Three studies achieved appraisal scores of over 50% indicating that

five or more assessment criteria were met and one study achieved an appraisal score of 30% indicating criteria were met for only three out of 10 assessment criteria.<sup>40</sup> With the exception of three studies,<sup>44-46</sup> none of the included studies identified the philosophical perspective underpinning the research design. However there was congruity between the research methodology and the research question or objectives and appropriate methods such as interviews and or focus groups were utilized to collect data for all studies with the exception of one,<sup>47</sup> in which the research methodology was not well detailed. Six of the 21 studies,<sup>41,42,44,45,48,49</sup> identified the beliefs and or values of the authors from a cultural or theoretical perspective in relation to the research and a statement identifying the influence of the researcher on the research and vice-versa was addressed in six studies.<sup>5,41,44,45,48,50</sup> However, all included studies were scrutinized and approved ethically by an appropriate body.

**Table 1: Methodological quality of studies**

Citation	Question										
	1	2	3	4	5	6	7	8	9	10	/10
Bassett, S. Stewart, J. Giddings, L. (2012) <sup>51</sup>	N	Y	Y	Y	Y	N	N	Y	Y	Y	7/10
Bognar, S., Defaria, AM. O'Dywer, C et al (2017) <sup>52</sup>	N	Y	Y	Y	Y	N	N	Y	Y	Y	7/10
Crizzle, AM., Newhouse, IJ. (2012) <sup>5</sup>	N	Y	Y	Y	Y	N	Y	Y	Y	Y	8/10
Davis, JT. Erbart, A. Trcinski, BH et al (2003) <sup>53</sup>	N	Y	Y	Y	Y	N	N	Y	N	Y	6/10
Elsworth, C. Dawes, H. Sackley, C. et al (2009) <sup>46</sup>	N	Y	Y	Y	Y	N	N	Y	Y	Y	7/10
Erikson, BM. Arne, M. Ahlgren, C (2013) <sup>42</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Hammarlund, CS. Anderson K. Anderson, M. et al (2014) <sup>47</sup>	N	Y	Y	Y	Y	N	Y	Y	Y	Y	8/10
Hislop, J. Gray, S. Melling, S. et al (2015) <sup>54</sup>	N	Y	Y	U	U	N	N	N	Y	U	3/10
Houston, S. McGill A. Lee, R. et al (2015) <sup>45</sup>	N	N	Y	U	Y	N	N	Y	Y	Y	5/10
Jones, D. Rochester, L. Birlson, A. et al (2008) <sup>50</sup>	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/10
Khalil, H. Busse, M. Quin, L et al (2017) <sup>55</sup>	N	Y	Y	Y	Y	N	N	Y	Y	Y	7/10
Khalil, H. Nazzal, M. Al-Sheyab, N. (2016) <sup>56</sup>	N	Y	Y	Y	Y	N	N	Y	Y	Y	7/10

Kunkel, D. Robinson, J. Fitton, C et al (2017) <sup>57</sup>	N	Y	Y	Y	Y	Y	N	Y	Y	Y	8/10
O'Brien, C. Clemson, L. Caning CG. (2016) <sup>43</sup>	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9/10
O'Brien, M. Dodd, KJ. Bilney, B (2008) <sup>44</sup>	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	10/10
Pretzer-Aboff , I. Galik, E. Resnick B. (2009) <sup>58</sup>	N	Y	Y	Y	Y	N	N	Y	Y	Y	7/10
Quinn, L. Busse, M. Khalil H. et al (2010) <sup>59</sup>	N	Y	Y	Y	Y	N	N	Y	Y	Y	7/10
Ramasamy, B. (2015) <sup>48</sup>	N	Y	Y	U	Y	Y	Y	N	Y	U	6/10
Ravanek, MJ. Schneider MA. (2009) <sup>30</sup> ,	N	Y	Y	Y	Y	N	N	Y	Y	Y	7/10
Sheehy, TL. (2014) <sup>49</sup>	N	Y	Y	Y	Y	Y	N	Y	Y	Y	8/10
Westheimer, O. Mcrae, C Henchcliffe, C et al (2015) <sup>60</sup>	N	Y	Y	N	Y	N	N	N	Y	Y	5/10

Y=Yes; N=No; U=Unclear; N/A=Not Applicable

Question:

1. Is there congruity between the stated philosophical perspective and the research methodology
2. Is there congruity between the research methodology and the research question or objectives
3. Is there congruity between the research methodology and the methods used to collect data
4. Is there congruity between the research methodology and the representation and analysis of the data
5. Is there congruity between the research methodology and the interpretation of the results
6. Is there a statement locating the researcher culturally or theoretically
7. Is the influence of the researcher on the research, and vice-versa, addressed
8. Are participants, and their voices, adequately represented
9. Is the research ethical according to current criteria, or for recent studies, and is there evidence of ethical approval by an appropriate body
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data

### **Characteristics of included studies**

The 19 included studies provided data on the views of pwPD in relation to their experiences and preferences for PA, their perceived enablers and barriers to engagement, and views on support mechanisms to promote engagement and sustained participation in PA. Qualitative data from the included studies were analyzed using grounded theory,<sup>44-46,51</sup> phenomenology,<sup>30,49</sup> and qualitative aspect of mixed methods design.<sup>47,52-55</sup> Several of the included studies<sup>5,50,56-59</sup> did not state the specific qualitative method used. Sample sizes ranged from one to 53 participants with a mix of genders. Where stated the Hoehn and Yahr stages of participants ranged from stages one to three (mild to moderate disease severity) with the exception of three studies,<sup>48,55,57</sup> that included participants up to stages four (able to walk but dependent for all Activities of Daily Living (ADL) and five respectively (wheelchair dependent).<sup>60</sup> The studies were carried out in United Kingdom (n=5), United States of America (n=4), New Zealand (n=1), Canada (n=3), Sweden (n=2), Australia (n=2) and Jordan (n=2). Nine of the included studies explored the experiences of pwPD who undertook a variety of physical activities including walking,<sup>48,50,52</sup> dance,<sup>47,54,55,59</sup> and exercise programs.<sup>44,46</sup> One study explored the meaning of exercise and factors that influenced exercise behavior.<sup>45</sup> One study explored the feasibility and cultural challenges of undertaking a home exercise program in Jordan.<sup>61</sup> Six studies<sup>5,46,51,53,56,57</sup> explored pwPD perceptions of motivators and barriers to PA. Only one study specifically explored how social support influenced PA participation.<sup>30</sup> No studies explored the experiences or views of pwPD towards behavioral interventions designed to aid PA participation. Findings are presented as synthesized finding with a sample of illustrative quotes. See Appendix V for a complete list of study findings, synthesized findings and illustrations

### **Findings**

Eight synthesized findings were identified: This consisted of 20 categories and 105 findings from 19 papers.

Table 2 provides a synopsis of the results of the meta-synthesis of the research findings.

Table 2: Findings, illustrations, categories and synthesised findings  
Objective 1 Explore pwPD Experiences and preferences for PA

Author (date)	Findings	Illustration	Categories	Synthesized Findings
Bassett et al (2012)	Physical and psychological wellbeing: When using the poles, the participant found she could overcome some of her physical and psychological limitations [U]	"The poles opened up my world again. I am not so overwhelmed on social occasions. I used to hesitate going where I knew there was going to be a crowd - especially if there was a possibility that there would not be seats provided. Now I just take my poles and use them as supports and that helps. ...". Participant pg 120 [U]	1.1 Activities improve symptoms and have a positive impact on wellbeing and quality of life and increase confidence.	1. Participating in PA is seen as positive, participants report improvements in physical and psychological function and symptom control. Participating in PA leads to holistic changes, including a sense of achievement, improved confidence and wellbeing.
Bassett et al (2012)	General health: Participant noted that over the Nordic walking phase, changes occurred in her general wellbeing especially with her appetite, sleep and energy levels. [U]	"After a couple of weeks of Nordic walking I actually felt hungry again !... I hadn't realized that I had not felt that for a while. I had been worried about having to use sedatives to sleep. A few weeks into the programme... I cut my dose and found I was able to get back to sleep after waking in the night." p120 [U]		
Bognar et al (2016)	Dance and the mind: Participants reported that the class provided opportunities to coordinate their body in new ways and promoted use of different areas of the brain. [U]	"[The brain] gets exercise at Dancing with Parkinson's because most dances are more than one step... when they give me the second thing to do at the same time... I notice it immediately." [P9] pg4 [U]		
Bognar et al (2016)	The emotional experience: participants agreed that attending the dance class improved their mood. [U]	"... you grab a partner and go around, and she smiles, but can't speak and she's happy. Emotionally it affects me as well because it's my benefit to make her happy" [P8] pg4 [U]		
Crizzle et al (2012)	Improved psychological well-being from perceived physical benefits: Participants noted improvement in their normal everyday activities. [U]	Participant 1 "I find it so much easier to reach for items in shelves that I had difficulty getting to before. I can also cut my meat and vegetables better. I feel like I can put more pressure on the knife. Such little things, but these play a big part of my daily living. I can't believe these things can be improved just by exercising". P1 pg180 [U]		



Author (date)	Findings	Illustration	Categories	Synthesized Findings
Hammarlund et al (2014)	Independence and Integrity: Participants felt that the ability to walk was important in managing their daily activities and work and was central to participation in life like everyone else. [U]	"Being mobile, to be able to participate in life normally, to be able to move around, take the train, drive the car... to be able to walk to different things without any trouble." Participant pg 660 [U]		
Houston et al (2015)	Balance and stability: Participants have mentioned an improved sense of body awareness both inside and outside of the dance studio with participants also noting a lack of freezing. [U]	"I get a bit of freezing in movement, but I feel I'm less freezing when I come to class. I don't freeze here and when I go back home I don't freeze as often that day." P pg 22 [U]		
Houston et al (2015)	Progression of Parkinson's: Participants noted that the physical changes may not be as obvious or distinctive as the mental benefits. [U]	"It's not just I'm in the mood, but physically I feel different. I don't think about it all the time, but suddenly I realise how much better I feel. More movement, more energy, certainly more energised.... I want to stay positive and not think about Parkinson's." Participant pg 24 [U]		
O'Brien et al (2008)	The outcomes were broader than just physical outcomes: participants said that there were no significant physical gains, yet they commented favourably about their experiences. [U]	Participant 8 said: 'I haven't noticed anything physically; maybe just a marginal improvement in the strength of my arms. With regard to my legs, I don't think there has been much change at all, but mentally I think, oh I don't know, I think just being involved with other people sort of, even at this level, helps me a bit.' Pg 1354 [U]		
Sheehey (2014)	Psychological outcomes: being in the programme and improving physical competence allowed participants to express surprise at their ability and a new-found confidence and realization that they have new possibilities. [U]	"It just gives you an all-over good feeling that you can, you can do it and, uh, I would never have thought, before I had the Parkinson's, that I could do anything like this." (Silvia) pg 35 [U]		
Westheimer et al (2015)	The participants reported benefits related to QOL and wellbeing that were not reflected in changes on quantitative measures. [C]	Less helpless; "doing something to help myself" Table 5 pg1628 [C]		

Author (date)	Findings	Illustration	Categories	Synthesized Findings
Erikson et al (2013)	Having feelings of coherence: The achievement of attending an exercise program and having support by the regularity and the promoting of the programme were important facilitating factors for those participants. [U]	"... I think it's very good with that hour that... at least once a week gets... the muscles there and there ... and do something. ... I feel satisfaction by being able to participate... that is the primary thing, I think. And ... also to feel that the body manages, because... I sometimes think when we're exercising, that we are incredibly capable considering our capacity. And sometimes you're not capable at all, but ... then when you experience that "Oh god, I can do this" then you get a kick..." participant pg 2242 [U]	1.2 Regular achievement of physical activity	
Erikson et al (2013)	Experience well-being through accomplishing: focused on an aspect of well-being that derived from the satisfaction of the achievements in itself [U]	"... the body feels good, he say "oh, it's so good that you've done this" and so on and ... it's difficult to say what it is but... I think I feel very good when I've achieved something." Participant pf 2242 [U]		
Davis et al (2003)	Functional mobility: Participants identified additional areas that were problematic; decreased mobility in bed; transfers from sit to stand as well as solutions. [U]	"Moving around in bed is almost an impossibility. There seems to be so much resistance between the sheets and it just seems impossible" participant pg40 [U]	2.1 Impact of PD is individual and unpredictable and presents challenges with functional activities and a loss of identity as an active individual; these can be a source of tension	2. PD is perceived to impact on all aspects of PA with temporal fluctuation in symptoms presenting both emotional and physical challenges. Changes to the level and type of PA and the use of individual
Davis et al (2003)	Walking: Participants identified 4 specific symptoms that affected their ability to walk; difficulty initiating movement, shuffling, festinating gait and freezing. [U]	"It affects the first step I take, the second and third steps are a lot easier than the first step. So, if get pointed in the right direction, and I get moving, I can continue moving but that first step can be a real challenge sometimes." pg40 [U]		
Davis et al (2003)	Falls: Issues pertaining to falls included their unique experience of falling, how falls have impacted their life and measure they have taken to prevent future falls. [U]	"I think balance is probably for me the worst thing... I've had one fall, but I'll remember that 'til they bury me, that sudden realisation of what happened. Fortunately, I was in my bedroom and fell on the nice carpeted floor, but it was a hell of a sensation." participant pg 40 [U]		

Author (date)	Findings	Illustration	Categories	Synthesized Findings
Davis et al (2003)	Medication cycles were recognised as a leading contributor to participants' physical limitations. [U]	"I noticed my problems walking are dependent on my medication... I skip my medication, my balance gets bad, I lose my stride, and I feel uncomfortable walking." pg41 [U]		strategies is used to maximize participation.
Hammarlund et al (2014)	Emotional reactions: Walking difficulties were perceived as aggravating and problematic, causing feelings of sadness and hopelessness. Struggling with activities resulted in frustration and anger. [U]	".... It's draining your energy and it saddens me. You become angry with yourself when it's hard and things don't work as you want them to. When you do something, things that you've done a hundred times before with ease, take forever to do today." participant pg 659 [U]		
Hammarlund et al (2014)	Social consequences: Walking difficulties had an impact on the ability to participate in social activities within or outside the family. [U]	"... it changes the whole lifestyle. You don't want to be amongst others. You back away from being in a crowd ... and at various events one feels like an outsider. I simply can't keep up anymore, not like I used to." participant pg 660 [U]		
Hammarlund et al (2014)	Changed walking ability: participants described gait had become slower, they were dragging their feet or steps could be tripping and the feet could get stuck to the ground. [U]	"So .... I felt like I sort of walked and dragged a little on ... a little like an old man, sort of dragged my feet." participant pg 659 [U]		
Jones et al (2008)	Walking 'after' – walking following another activity: Participants noted an increased difficulty in walking after an activity. [C]	'Increasingly manoeuvring out of dining chairs at a table; rolling to the edge of the bed in order to get the legs over the edge; exiting the bath; turning after standing were reported as challenging, especially in the 'off' state. Initial walking after all these activities was likely to be characterised by shuffling steps, potentially stooped posture, often accompanied by unsteadiness...' (author pg 11) [C]		

Author (date)	Findings	Illustration	Categories	Synthesized Findings
Jones et al (2008)	Walking 'in' – walking in different environments: outdoors posed unpredictable challenges and were disliked. Indoors doorways and furniture, the need to constantly change direction and to change positions caused the main challenges. [U]	'Having to stop, start and change direction; being jostled; coping with distractions; feeling pressured and self-conscious; and having to concentrate on yourself and others, were all tiring and often frightening.' (author pg 10) [U]		
Jones et al (2008)	Walking whilst- walking while doing something else: participants noted that undertaking dual tasks could become challenging. [U]	"Sometimes if I concentrate too much on not spilling the tea I sort of forget about going up the stairs ... It's as if my nervous system is overloaded. Can't unscramble the two messages" (P17 pg 9) [U]		
Kunkel et al (2017)	Managing potential sources of tension or difficulty: It was potentially problematic, both for novice and experienced dancing couples, when a male dancer with Parkinson's found it difficult to fulfil the traditional role that was expected of him. [U]	Person with Parkinson's: She irritated me to the extent that I said, "Look I'm supposed to be leading here!" and she said "Yes, but you're not doing it right!" [laughing] Andrew age 73 H&Y3 block 1) pg 5 [U]		
O'Brien et al (2013)	Loss of ability and loss of identity as active self: Participants identified a variety of physical and mental changes attributable to both PD and ageing that caused reduced ability to engage in physical activities and consequently led to adaptations in the way they participated in them. [U]	"It's just the limitations of not being able to do things you used to be able to do. You move into a stage where you can't do things that you used to be able to do and I miss very much not having a license to drive a car and so I'm sort of housebound except for my wife, my wife drives me places but it's hard on her too, so it's a hard time." P7 pg 3 [U]		

Author (date)	Findings	Illustration	Categories	Synthesized Findings
Pretzer Aboff et al (2009)	Communication Difficulties: Difficulty writing and speaking because of tremor, hypophonia, and freeze episodes were described as hampering the ability to communicate with others. [U]	"I cannot write. There is a stack of condolence letters here, from when my wife died. I initially said I will answer each of them myself. I had all the intentions of doing so, but I couldn't write. So, I decided that I could do it all with a machine, on the computer. But I couldn't do it on the computer because I couldn't type either. Now I can't hit the right key for nothing." No pg no. [U]	2.2 coping strategies are individual to the person.	
Davis et al (2003)	Altering performance of activity of daily living: participants managed ADLs by altering how they were achieved including; increased time and being organised [C]	'Some participants acknowledged organising and taking advantage of the productive time when their medication was 'on'. Example of preparation were writing out checks before going to the store and organising commonly used areas into workstations that were equipped with frequently needed items.' (author page 41) [C]		
Davis et al (2003)	Participants coped with the disease by attempting to maintain a sense of normalcy. [C]	'One participant explained how she hid her foot, which showed dyskinesia, under the desk, to prevent co-workers from discovering that she had PD.' (author pg 41) [C]		
Davis et al (2003)	Participants identified coping with the disease through maintaining a positive outlook. [U]	"Every once in a while, I think, 'hey, I'm lucky I have Parkinson's', I have friends who have had lung problems, who have had heart attacks, total loss of vision and are buried. We are alive" P pg41 [U]		
Hammarlund et al (2014)	Strategies to manage the impact of walking difficulties: They chose to accept the new situation, to plan their lives in both the long and short term, using cognitive strategies to overcome difficulties. [U]	"if I know that I am doing something special then I have to adjust my medication accordingly. And you have to constantly think, think ahead, plan a little more of your activities in relation to the medication and so.... It has clearly changed my life, it really has..." participant pg 659 [U]		
Houston et al (2015)	Posture: Participants note the challenge in maintaining posture in relation to dance and the difficulties in maintaining posture outside of the class in order to cause permanent change [U]	"I think when I go off and I remember to walk so tall, and keep my head up, and swing my arms, just to do movement, and if I think I go dancing and sit up straight, and shoulders back, head up, it's a great image to hold on to." Participant pg 22 [U]		

Author (date)	Findings	Illustration	Categories	Synthesized Findings
Jones et al (2008)	Monitoring: walking using concentration: Participants needed to monitor walking quality and consciously correct deficits. [U]	“ ... but I’m always watching, thinking, terrified of falling over but there’s that feeling always that you must watch where you are going.” (05). Pg12 [U]		
Jones et al (2008)	Correcting: Walking through generating rhythm and size of steps. Imagined or actual visual input was used to start and maintain stepping and overcoming freezing. [U]	“I had to rehearse mentally if I was going to take a step and then take the step.” (20). Pg 13 [U]		
Davis et al (2003)	Physical limitations and compensatory strategies: participants shared similar physical limitation related to PD, however, the way in which these limitations affected each participant was unique. [U]	“With this disease you have similarities, you know they are just similar and at other times it’s like your disease is custom made to you.” Participant pg 40 [U]	3.1 Participation in physical activity is affected by disease presentation and is highly individual	3. Participation in PA is highly individual, with participants valuing activities which are perceived as personally relevant and tailored to their needs and preferences. Participant perceptions of PA are affected by expectations and self-evaluation of progress.
Erikson et al (2013)	Trusting own experiences: meant being attentive to the signals from one’s body and acting in the best way according to one’s knowledge, beliefs and experiences. [C]	“... I keep myself a bit busy at home... I have recorded a lot of tunes ... and do certain exercise there... and so on. So ... I rarely sit still... if I put it that way.” Participant pg 2240 [C]		
O'Brien et al (2008)	Indicators of success for participants varied: Participants said they used several methods to judge whether they were progressing in the programme or not. [U]	“I did feel that I was working as I went through the bands, the stronger bands, that, yeah, it did seem to get easier as I went along, particularly with the legs. Much easie.” (Participant 12), pg 1354 [U]		
Pretzer Aboff et al (2009)	Personality components: Participants spoke of personality traits that promoted independence in physical activities such as resilience, determination, need for independence, denial of need for assistance, and humour. [U]	“I don’t ever call for help, really. I try to stay independent.” Participant no pg no. [U]		

Author (date)	Findings	Illustration	Categories	Synthesized Findings
Houston et al (2015)	Participant expressed what was important to them personally in maintaining a good quality of life [C]	'Having confidence to do things / having the ability to keep doing interesting activities /having movement capability and stability / being around loved ones / having a religious belief.' Author pg 25 [C]	3.2 Participants report individual preferences for the setting for PA. Tailored goals and self-evaluation of progress are important considerations for their engagement	
Khalil et al (2016)	Setting-related issues: location of the exercise was considered important for the participants to engage in an exercise program with some preferring home and others hospital [C]	"The commitment to the program will be better if it is at the hospital and under the supervision of a therapist. At home, you may get busy with other stuff; defer the exercises and end- up of not doing them." P1 pg 514 [C]		
O'Brien et al (2016)	Identifying goals: participants had their own individual goals, therefore each participant had different goals and expectations from the program and these were often different from the physiotherapists' goals. [C]	"I believe that at my stage of Parkinson's progress that I have to be concerned about power and balance.". P6 Pg 6 [C]		
O'Brien et al (2016)	Evaluating if expectations are met: and the outcome of this evaluation was continually changing. [C]	"You can get disappointed if you can't do it. P1 The effort really means a lot, but I just sort of glided it through somehow to get it finished ... I didn't do it to my satisfaction." P3 pg 6 [C]		
Quinn et al (2010)	Barrier: location of exercise Lifestyle issues - some of the clients preferred doing exercises at home rather than going to the gym, because it would fit better with their lifestyle. [U]	PD2: "I tend to exercise at home rather than going to the gym because it fits in with my lifestyle really. At the weekend I have my granddaughter and also I am working three times a week." Table III pg 922 [U]		
Crizzle et al (2012)	Reassurance from instructor: was an important motivator of exercise adherence. [U]	P4 "A few people started off better than me... and that bothered me. But the instructor told me not to worry about it and that I should work at my own pace. I didn't think I could do it. I nearly gave up. But the leader always insisted that I could do it, so I had to prove myself and then I could." pg180 [U]	4.1 Reassurance and support from group members, instructor, partner or family are important for participation in physical activity; while	4. External factors can affect participants' experience of PA. Involvement of



Author (date)	Findings	Illustration	Categories	Synthesized Findings
Houston et al (2015)	Fluency of movement: participants have a perception that music helps people to move in a more fluid and coordinated fashion. [U]	"The dance made me feel more graceful, moving and flowing with the music, it made me feel that I had to move when the music started." P pg 19 [U]	the use of music enhances enjoyment	family members/ friends and use of music make sessions enjoyable and increases wellbeing. Support from instructors to ensure PA programmes are structured and simple to undertake, to explain the relevance of activities and to support progression give participants confidence and enhances their participation.
Kahil et al (2017)	Continuous monitoring: Participants perceived the importance of initial instructional sessions and the weekly phone calls as important elements for initial adoption of the program and also for continuation; they were perceived as important aspects of the program to build self-efficacy [C]	"I really prefer doing the exercises at home ... the sessions with therapist were very important to know what I am supposed to do and to build confidence." (table 4 no page no.) [C]		
Kunkel et al (2017)	Views on the experience on being partnered with their spouse or volunteer: participants who danced with their spouse or somebody else they knew well, appreciated not only the practical convenience but also the sense of "moral support" and shared enjoyment that this afforded them [U]	Person with Parkinson's: "I wouldn't have liked, I wouldn't have gone if [husband] hadn't have been my partner I don't think. I liked that very much, I liked it a lot." [Brenda: F, age 81, BLOCK 3 pg3 [U]		
Pretzer Aboff et al (2009)	Environmental Factors: including the social support network, members of the healthcare team, and the physical environment were identified as either facilitating or challenging the person's day-to-day ability to function [C]	'Participants noticed that small spaces, clutter, and stairs decreased mobility.' Author no page no. [C]		



Author (date)	Findings	Illustration	Categories	Synthesized Findings
Bassett et al (2012)	Experience of the Nordic Walking programme: The progressive manner in which the walking phases were implemented gave the participant confidence with her walking: [U]	"Starting on flat surfaces first, that are not near road traffic - like at the park and university grounds, meant / could concentrate on Nordic walking; I didn't need to think about where I was going... That helped with my confidence so that I was not distracted by all the road noises and people going past. After six weeks, I became less conscious of the poles; I did not need to think all the time about how to walk with them. The poles became an extension of my arms. Once I had mastered all of what is involved, I found I was self-correcting and walking quite confidently." p120 [U]	4.2 Supervision from an instructor who can provide education on the benefits of exercise as well as prescribe and progress exercises enhances participation	
Houston et al (2015)	Cognitive Functioning: Participants find the dance classes to be quite difficult with respect to remembering the movement sequences and being able to move different parts of the body simultaneously. [C]	"I do think it is good for you. The whole mental activity is on a different plane from physical activity." Participant pg 25 [C]		
Khalil et al (2017)	Social interaction and relation with the therapist: was a strong motivator to adhere to the program. [U]	"For the first time ever I felt that someone was truly taking care of me that was the best piece of the intervention. It made me feel in turn that I should take care of myself by committing to the exercise program. The therapist was an excellent motivator." (table 4 no page no.) [U]		
Quinn et al (2010)	Setting targets and having knowledge of benefits of exercise: Clients felt that their understanding of the relevance and usefulness of exercises was most critical to determining whether or not they participated. [U]	PD5: "I think it should be clear how the exercises fit into the program. That's helpful. If I feel that the exercises make a difference, then I can do them more. Also having the general idea of the benefits of doing the exercise. I think the exercise is good for me and by doing the exercise I appreciate that there is a difference." Table III pg 923 [U]		
Khalil et al (2017)	Enablers: Participants reported that DVD was very clear, easy to follow and provided an important tool to	"The DVD was simple and easy to follow its use at home was a strong motivator to continue doing the exercises." (table 4 no page no.) [U]	4.3 Simplicity of exercise programme	

Author (date)	Findings	Illustration	Categories	Synthesized Findings
	continue performing the exercises independently at home [U]			
Quinn et al (2010)	Simplicity of exercise program. [U]	PD5: "Sessions with physiotherapist actually taking me through with the exercises; that is good I think. They gave me exercises to do at home, but I have not continued using them because of a couple of things actually. For back exercises there was no standard to do them. So, you do a lot and a lot of exercises like the hand behind the shoulder or the hand in front but actually you do not know what for the exercises are and the differences are tricky . . . I think exercises should be simple and clear how they fit into the program. That's helpful.". Table III923 [U]		

Objective 2. Explore pwPD barriers and enablers to PA

Author (date)	Findings	illustration	Categories	Synthesized finding
Khalil et al (2017)	Perceived improvement: whether in physical or mental status was a key to motivate them to adhere to the exercise program [C]	"The exercise program has affected me both mentally and physically before I got to know you and was introduced to this program I used to lock myself away at home fear of falling was a big issue. I was therefore not moving ... Now my mobility has improved dramatically ... I feel as If I have regained big chunk of my life." (table 4) [C]	5.1 Perceived improvement in wellbeing and physical activity aids motivation to participate in PA	5. A personal desire to maintain independence and a belief that physical activity can slow deterioration are driving forces for participation. Motivation is enhanced by perceived improvement in
Khalil et al (2016)	Outcome expectations: positively affect the participant's decision about getting engaged in a future exercise program [U]	"My health is my priority and if exercise would help then I will exercise daily. I really would like to reach that level of doing things by my own and not relying on others; this is all what I want." P4 pg 515 [U]		
Sheehy et al (2014)	Physical ability: participants identified improvements in physical competence post programme [C]	"I wanted to do everything I could to delay, I think, keep active and delay if, if possible any progression" (Fiona) participant page 32 [C]		

Author (date)	Findings	illustration	Categories	Synthesized finding
Quinn et al (2010)	Benefits of group exercise. [U]	PD4: "I think if you want to do the exercise by yourself, it will be very difficult to motivate yourself. If you were in a class which is not necessarily a class of Parkinson's but a class of people in the same fitness range as you and it is organized in a daily or weekly basis, you can along with it. There is the social aspect as well." table III pg 922 [U]		symptoms and feelings of accountability to oneself or others.  5.2 Personal desire to maintain function and or slow progression of symptoms is a key motivator for continued participation in PA
Bognar et al (2016)	Dance and the body: participants reported a desire to maintain their current functional status and to slow physical deterioration as motivation for continued participation [C]	"It has led to some fluidity, which might not have been there in the body earlier." [P1] pg4 [C]		
Erikson et al (2013)	Have to keep on moving: was a driving force for exercise, emanating from sustaining self-image, believing in the benefits of keeping oneself active was the underlying construct [U]	"And... then it's my goal to try to keep myself ... keep myself on the go as long as possible so that I ... yes, to be part of life. Not only to sit on a park-bench and ...hear somebody talk ... but ... to be active as well as I can..." participant pg 2241 [U]		
O'Brien et al (2008)	Motivators for participation were broader than just physical outcomes: they gave a number of reasons for why they chose to take part in the study [C]	Participant 1: "[I] was keen to try and assist the program as a participant for the sake of future generations of PD sufferers." Pg 1353 [C]		
O'Brien et al (2016)	Focusing on not losing more: adapting to loss of physical ability also involved focusing on what participants could do and trying to prevent further losses. [U]	"I'm just trying to hold on to what I have. I mean I am quite old. I really felt that I must not overburden the body." P2 pg 4 [U]		
Ravanek et al (2009)	Perceptions of control: participants viewed physical activity as a means to slow the progression of the disease, and help maintain their independence	"I have no other answers with this, with this disease . . . it's something I want to try and fight . . . and I don't know how to fight it [pause]. I don't want to be overmedicated. I'm hoping exercise can flatline it or slow down the progression or help		

Author (date)	Findings	illustration	Categories	Synthesized finding
	[U]	me. I don't know. So, it's mainly my decision to [participate in physical activity]." Participant pg 1933 [U]		
Bassett et al (2012)	Experience of the Nordic Walking programme: Walking with a designated person enhanced commitment [U]	"I think having a commitment to meet someone at a specific planned time was most important. Let's face it; what I really felt like doing some mornings was to stay in bed! It would have been easy to make excuses to myself if I did not know I had to meet you." Participant pg 120 [U]	5.3 Personal obligation to oneself and supportive others ensures a commitment to exercise	
Erikson et al (2013)	One should see to one's health: a knowledge-driven obligation towards oneself and toward supportive significant others and health professional, that exercise is necessary to good health. [U]	"One tried to do (exercise) as well as one can in everything and ... doesn't try to waste time in any way but tries to do as well as possible. ... because the doctor said that ... exercise is very important for everybody ... for everybody who has Parkinson's disease... so I mustn't become an idler so ...out and ...yes walk a lot with poles to keep up the agility in arms and shoulders." Participant pg 2241 [U]		
Erikson et al (2013)	Taking responsibility for own health: generated from the decision making that preceded start to exercise and included the decision to believe in the good effect of exercise and the counteracting effective of a passive lifestyle [C]	".. and then its only making the best of the situation... one mustn't think negatively, one has to try to avoid that... think positively, try turning everything into the best instead." Participant pg 2241 [C]		
O'Brien et al (2016)	Comparing oneself with others in the exercise group: was another aspect of exercising in a group of people with PD.[U]	"That was an incentive for me to put more into it because I could see that one guy in particular was benefitting from it." P6 pg 6 [U]	6.1 Favourable or unfavourable comparison with others can be a	6. Participants report that personal characteristics

Author (date)	Findings	illustration	Categories	Synthesized finding
Ravanek et al (2009)	Social support groups: An important factor contributing to the perceived suitability of these groups for participants was the variability in disease progression of group members. When participants were not able to relate to other group members, the support groups were seen as negative and this led to attrition. When participants were able to relate to other group members, these groups offered a tremendous amount of support. [U]	"I went a couple times [to a support group] but they're all, I hate to say it, quite elderly and that for me personally is very depressing . . . They're all a lot worse because they've had it longer so they're very few young people . . . So, we went to the social group but it's like being at a senior's centre . . . so I haven't gone after. . . . It is really depressing to see what you have to look forward to becoming." Participant Pg 1932 [U]	motivator or barrier to engagement	such as exercise habit, information seeking, resilience, problem solving and interest in the activity are motivators for engagement. However, lack of time, low outcomes expectations and cultural challenges are seen as barriers. Comparisons with others can be a motivator or barrier to engagement
Sheehy (2014)	Social comparison: made with others varied based on disease and ability and resulted in both positive and negative emotions [U]	"When you talk to other people then, that have been doin' this, like, [Marty] for thirteen years and she's in my class and they're doin' better than me, much better than me...I think, we'll see, you know, there's a good possibility that thirteen years from now I might be where I am." (Belle) pg 33 [U]		
Bognar et al (2016)	Redefining the self: seeking knowledge to become proficient in self-management [U]	"Going to class you're not giving in – you're getting back. You're getting something to help yourself." [Participant 2] pg 4 [U]	6.2 Motivation for participation is influenced by personal characteristics.	
Davis et al (2003)	Being a self-advocate was a method of dealing with the disease. [U]	"Unless you are lucky enough to have a nurse practitioner like - --- or you find a good physical therapist, you have to be an advocate, you have to say 'I want physical therapy, what can you write me a prescription for? I want to go and be evaluated about how to use a car or I want to learn about how to get my oxygen better' ... so I feel that you have to gather information, you have to be an advocate and tell them what you want and hope that you have a good circle of family and friends". Participant Pg 42 [U]		

Author (date)	Findings	illustration	Categories	Synthesized finding
Erikson et al (2013)	Identifying oneself as physically active: related to the participant definition of themselves as a physical active person both in the past and in the present [U]	"...one was out running and doing aerobics and ... such things. I used to participate in those gymnastic displays we had at that time... and that was fun... of course that was a driving force... () and there the habit too ... (to exercise)." participant pg 2240 [U]	6.3 Barriers to participation in PA include a lack of outcome expectation, lack of time and cultural challenges.	
Erikson et al (2013)	Being Part of life: participants expressed an aim to continue to participate in valuable areas of life even if support was needed for managing to do so. [C]	"When you aren't disabled... you think that it's the practical things which are... the main thing, but it isn't. It's how you feel inside... and then... then it's not such a big defeat if you can't get your shoes on. What I mean with being part of life, it's probably to be needed." Participant pg 2240 [C]		
Houston et al (2015)	Aid to daily life: Participants noted how exercise from class help to alleviate rigidity and pain and improve mobility for everyday activities. [U]	"It is typically a matter of identifying the right exercises on each occasion to alleviate the various neuro-muscular afflictions. For my shoulder I noted during the classes that the 'lasso, arrow and sword' provided some temporary relief – so, I used a similar routine at home to improve mobility and it seems to work better than anything else I have tried (e.g. stretching and strengthening)." participant pg 26 [U]		
Kahil et al (2017)	Personal challenges: comorbidities such as knee or hip osteoarthritis, cervical or lumbar disk, limited but did not prevent them from engaging in the exercise program. [U]	"I have a chronic problem in my knee and some of the balance exercises were causing me more pain ... this did not stop me from doing the exercise ... the therapist helped me in modifying the exercise so that it became more tolerable." (table 4 no page no.) [U]		
Kahil et al (2017)	Lack of outcome expectations: one participant at early stage believed he was not necessarily in need for exercise as they were still physically fit. [C]	"I feel I am physically better than other people... and the nature of my work requires a lot of movements. I work as a plumber; hence I move all the time." (table 4 no page no.) [C]		
Khalil et al (2017)	Cultural challenges: being active is not the norm particularly for old people. [U]	"At home I have the fear that my sons will comment on this I am trying to avoid this. I did though all the sessions with the therapist in the clinic but did not do the sessions at home." (table		

Author (date)	Findings	illustration	Categories	Synthesized finding
		4 no page no.) [U]		
Kunkel et al (2017)	Views on continuing with dance classes: all people with Parkinson's expressed an interest in continuing to dance but none had made firm arrangements to do so. [U]	Person with Parkinson's: "I think it, because I can't walk that far, and I can't walk that quickly, certainly regular dancing would take the place of some of the walking that I can't do." Elizabeth: age 71, H&Y2, pg 6 [U]		
Kahil et al (2017)	Depression: affected motivation to do anything including getting engaged in the exercise program. [U]	"Since I've been diagnosed with PD and I felt low...I became less motivated to do anything in life ... even when you invited me to do the exercises I felt apathetic." (table 4 no page no.) [U]	7.1 Disease specific barriers: both physical and mental are identified as a barrier to participation in PA	7. Difficulty obtaining an initial diagnosis, accessibility of services, disease symptoms (both physical and psychological) and severity all impact on pwPD's ability and desire to undertake physical activity.
Kahil et al (2017)	Participants perceived that Physical fatigue would limit but not prevent them from engaging in the exercise program. [U]	"I lacked the habit of past exercise. This is the first time I have been in a structured program. When I first started, I used to feel tired even after performing only a few movements. This feeling, however, ceased off after few weeks." Participant (table 4 no page no.) [U]		
Khalil et al (2016)	Disease-specific issues: such as stiffness and fatigue may limit their potential participation in future exercise programs. [C]	'All the participants reported experiencing the "wearing off" phenomenon in which these symptoms become much more apparent.' Author pg 514 [C]		
O'Brien et al (2016)	Facing challenges of apathy, fatigue and other health problems were a significant barrier to regular exercise participation. [U]	"You've got to battle with willpower all the time." P3 pg 5 [U]		
Pretzer Aboff et al (2009)	Physiological symptoms: both motor and non-motor, of PD were noted by people with PD to limit the ability to engage in physical and functional activities. [U]	Another participant described his experience with bradykinesia: "It is difficult. I muddle through. . . . It takes me forever . . . my speeds have gone from slow and stop." (no page no.) [U]		

Author (date)	Findings	illustration	Categories	Synthesized finding
Quinn et al (2010)	Disease specific barriers: Participants with PD, highlighted several factors, namely stiffness, fatigue and problems with maintaining concentration. [U]	PD5: "Having the disease does influence my ability to exercise, because I think it is hard to concentrate. So, focusing is difficult and also the tiredness and fatigue is another problem." pg 922 [U]	7.2 Participants identify difficulty gaining a diagnosis as well as lack of referrals to physiotherapy, lack of information about the benefits of exercise which are compounded by a lack of services and problems with access as barriers to participation	
Sheehy (2014)	Psychological challenges: participants feared doing a programme which was unfamiliar and where they may hurt themselves [U]	"I had all those kinds of fears. Well, you know, what if it's like one of those classes you go into and the person at the front is saying, no pain, no gain, and you hurt yourself and then you can't do anything." (Imelda) pg 32 [U]		
Davis et al (2003)	Health Care issues: the current health care system does not meet the comprehensive needs of individuals with PD. [U]	"it's kind of pitiful that we don't have outreach with physical therapy, we have no national, state or local outreach programs, look at the table of us, how much we would improve if we had one hour of outreach a week." pg42 [U]		
Kahil et al (2017)	Denial of PD diagnosis: participants at early stage were still in doubt of being diagnosed of PD. [U]	"I did not do the exercises because I am still not convinced I have PD ... I have this dilemma ... I am really not convinced that I have PD ... next week I will be seeing another neurologist to discuss my case." (table 4 no page no.) [U]		
Kahil et al (2017)	Participants report that compensation for transportation helped with adherence [U]	"As you know I come from a distance and my participation would have been impossible without covering the transportation costs that was really important aspect" (table 4) [U]		
Khalil et al (2016)	Difficulty of diagnosis: Participants with PD reported spending a huge chunk of time searching for a basic answer that can justify their symptoms: a diagnosis. [U]	"I started to feel symptoms 6 years ago, but I have only been diagnosed 2 years later. I was complaining of general slowness of movement and fatigue; simple things would become difficult. The GP excluded PD as it did not fit with my age category, However I doubted it was PD, as the symptoms were similar to my father's, who is also a PD patient. When other symptoms started to appear like tremor, the GP decided to refer me to a specialized neurologist." P5 pg 512 [U]		



Author (date)	Findings	illustration	Categories	Synthesized finding
Khalil et al (2016)	Lack of informational support by neurologist: about the importance of exercise or physiotherapy to their condition. [U]	"I do not do any specific exercises for managing my condition as I am not aware of any. . . my neurologist has not mentioned this to me." P9 pg 513 [U]		
Khalil et al (2016)	Lack of referrals to physiotherapy: None of the participants were referred to physiotherapy for explicit management of PD. [U]	"Four years ago I was complaining from lumbar disk and for that reason I've been referred to physiotherapy. The treatment was for my back pain but not for the PD." P3 pg 514 [U]		
Quinn et al (2010)	Lack of information on exercise in PD [U]	"I had not any advice as to exercises. We picked up some leaflets at one time in the doctor's surgery, from the PD society, but I don't think there was anything in there that referred to specific exercises or something that was relevant to me." Participant pg 922 [U]		
Ravanek et al (2009)	Physicians: participants' reports on GPs and neurologists was the lack of support provided with regards to physical activity participation. [U]	"[My] GP really didn't say much. Actually, neither doctor really encouraged [physical activity]. They didn't discourage it, but they didn't really come out and say, 'You should join this,' or 'You should do that.' There's probably a little bit more work that could be done there to keep people active." Participant pg 1931 [U]		

Objective 3. Identify from the perspective of pwPD the impact of support mechanisms in maintaining participation in PA

Author (date)	Findings	Illustration	Category	Synthesized finding
Bognar et al (2016)	Connecting through dance: the need for socialization was articulated as a central motivator for attending class, as participants admitted that living with PD could be isolating. [U]	"When you get a Parkinson's diagnosis, [you] tend to back into a cage somewhere where nobody can see my weaknesses. You tend to exclude yourself from society. When you join something like Dancing with Parkinson's you become part of a larger group and it's much easier to fight that weakness.... The other classmates are a benefit that I didn't expect or think about at the time." [P9] pg 3 [U]	8.1 Group physical activity offers a positive communal experience and provides opportunities for socialization, support and confidence building	8. Participants report group members, family, friends, and co-workers provide support for them to initiate and sustain physical activity
Westheimer et al (2016)	Physical social and emotional benefits of the group. [C]	"Very positive communal experience; pleased to see improvements in others participant." pg1266		

Author (date)	Findings	Illustration	Category	Synthesized finding
		[C]		
Crizzle et al (2012)	Group structure and group support: participants reported developing a good rapport with each other over time and were encouraged by the improvements made in their physical and social abilities. [C]	Participant 1 said (pointing to participant 4): "He actual talked to me later on, at the beginning he just sat there completely mum." pg180 [C]		
Hislop et al (2015)	Confidence building: Attendance at the group helped build confidence. [U]	"It gives you more confidence to go out in the world and tackle life. You know, if you've got a wee network of people that understand you..." participant pg 3 [U]		
Houston et al (2015)	Motivation to keep coming to the English National Ballet ENB Dance for Parkinson's programme were diverse. [U]	"I didn't know anyone with Parkinson's before I came to these classes. I was all alone. It's not just about dancing, it's making friends and sharing." P pg 27 [U]		
O'Brien et al (2008)	The participants' experience of a disease-specific exercise programme was positive: Benefits included sharing information about Parkinson's disease. [U]	"[We] exchanged thoughts and notes that we had we all seem to have been on the Internet at various stages, gathering information, and it was very helpful." (Participant 4). Pg 1355 [U]		
O'Brien et al (2016)	Relationships with a shared understanding: Participants valued the experience of exercising with others with PD. Having a common purpose and a shared understanding were common themes. [U]	"It's not that you want sympathy but understanding. So, when you're down there (referring to the group) I actually totally relax because we are all understanding each other." P2 pg6 [U]		
Sheehy (2014)	Social support: centred around the varied types of support given and received by participants [C]	"I just kinda take it upon me, you know, if I see somebody not doin' what they, you know, need to be doin' or goin' in the wrong direction, I, I just feel like I should help out." (Albert) pg34 [C]		

Author (date)	Findings	Illustration	Category	Synthesized finding
Kahil et al (2017)	Family support: encouragement provided by family members was perceived to be important. [U]	“The family encouragement was very important for me to take this step and start the exercise program with you.” (table 4 no page no.) [U]	8.2 Family support and encouragement to initiate and sustain PA	
Khalil et al (2016)	Family support: and commitment was perceived as an important element for some participants to initiate and maintain an exercise program. [U]	“Family has always been a source of support for me to accept the disease and to deal with it. A lot of mornings I would be very tired sitting on my sofa or lying in my bed until my son comes and asks me to go for a walk with him. His encouragement pulls me up and it's just about the start that is difficult then I get clicked on; I usually feel much better afterwards.” P9 pg 515 [U]		
Ravanek et al (2009)	Sources of support: Family members - the most salient forms of support provided by participants' families were instrumental and emotional support. [U]	“They encourage me, goad me, embarrass me into doing some [activities] and they also will alter their activities to accommodate me which is very good. [My husband] just you know, like he always is trying to get me into doing more. He probably encourages me and gets me going more than I would do myself.” Pg 1929 [U]		
Ravanek et al (2009)	Sources of support: Friends - The main forms of instrumental support were the provision of transportation and mutual participation in physical activity. [U]	“They'll come out and walk with me sometimes or friends will come out and bike with me . . . it's nice to have friends who are compassionate, and ah understand what you are going through.” Participant pg 1930 [U]	8.3 Support and encouragement from friends and co workers	
Ravanek et al (2009)	Sources of support: People in the workplace - This type of support commonly took the form of organising work schedules to allow for time to participate in specific exercise programs. [U]	“They were all very supportive because I started [exercising at the research centre] when I was still working. So, they all made sure, no matter who was working with me, that I got off in time.” P pg 1930 [U]		

Findings are organized into synthesized findings representing the three objectives of the study.

### **Objective 1: Explore pwPD experiences of and preference(s) for physical activity**

#### **Synthesized Finding 1.0:**

*Participating in PA is seen as positive; participants report improvements in physical and psychological function and symptom control. Participating in PA leads to holistic changes, including a sense of achievement, improved confidence and wellbeing.*

This synthesized finding was derived from 13 findings and two categories:

#### **Category 1.1 Activities improve symptoms, have a positive impact on wellbeing and quality of life and increase confidence.**

Physical activity was perceived to improve both physical and psychological symptoms of PD with both aspects deemed important for wellbeing. Improved physical and or psychological symptoms enhanced participants view of their quality of life and regular engagement in PA increased their ability to undertake functional tasks. Regular engagement enhanced confidence in their ability to partake in activities and opened up their world to new possibilities.

*"I find it so much easier to reach for items in shelves that I had difficulty getting to before. I can also cut my meat and vegetables better. I feel like I can put more pressure on the knife. Such little things, but these play a big part of my daily living. I can't believe these things can be improved just by exercising."* <sup>59(p180)</sup>

*"[It] just gives you an all over good feeling that you can, you can do it and, uh, I would never have thought, before I had the Parkinson's, that I could do anything like this"* <sup>49(p35)</sup>

*"The [Nordic walking] poles opened up my world again. I am not so overwhelmed on social occasions. I used to hesitate going where I knew there was going to be a crowd - especially if there was a possibility that there would not be seats provided. Now I just take my poles and use them as supports and that helps. ..."* <sup>52(p120)</sup>

#### **Category 1.2 Regular achievement of physical activity programs**

People with Parkinson's disease expressed a sense of achievement from attending and participating in a regular PA programs. The achievement was bolstered by the emotional and social benefits of undertaking PA in a group setting.

*".. I thinks it's very good with that hour that... at least once a week gets... the muscles there and there ... and do something. ... I feel satisfaction by being able to participate... that is the primary thing, I think. And ... also to feel that the body manages, because... I sometimes think when we're exercising, that we are incredibly capable considering our capacity. And sometime you're not capable at all, but ... then when you experience that "Oh god , I can do this" then you get a kick."* <sup>44(p2242)</sup>

#### **Synthesized finding 2.0:**

*PD is perceived to impact on all aspects of PA, with temporal fluctuation in symptoms presenting both emotional and physical challenges. Changes to the level and type of PA and the use of individual strategies is used to maximise participation.*

This synthesized finding was derived from 20 findings grouped into two categories:

**Category 2.1 Impact of Parkinson's disease is individual and unpredictable and presents challenges with functional activities and a loss of identity as an active individual; these can be a source of tension.**

People with Parkinson's disease identified difficulties with a wide range of physical activities and tasks and these difficulties varied depending on the individual and from day to day. Being unable to undertake a task could be a source of tension. Participants expressed a variety of emotional reactions including frustration and anger as well as sadness at the loss of activities that they were previously able to do. This often resulted in pwPD having to change their lifestyle with some withdrawing from society.

*Person with Parkinson's: She irritated me to the extent that I said "Look I'm supposed to be leading [here!]" and she said "Yes, but you're not doing it right!" [laughing]<sup>54(p5)</sup>*

*"... It's draining your energy and it saddens me. You become angry with yourself when it's hard and things don't work as you want them to. When you do something, things that you've done a hundred times before with ease, take forever to do today"<sup>48(g659)</sup>*

**Category 2.2 Coping strategies are individual to the person.**

Participants described a number of different strategies (which often involved cognitive effort) that they employed in order to walk and participate in physical activities, including use of equipment, planning, and timing of medication with avoidance of activities not deemed important. Maintaining a positive outlook was considered a key aspect of managing the disease as well as trying to maintain a sense of normalcy.

*"If I know that I am doing something special then I have to adjust my medication accordingly. And you have to constantly think, think ahead, plan a little more of your activities in relation to the medication and so.... It has clearly changed my life, it really has..."<sup>58(p659)</sup>*

*"I think when I go off and I remember to walk so tall, and keep my head up, and swing my arms, just to do movement, and if I think I go dancing and sit up straight, and shoulders back, head up, it's a great image to hold on to."<sup>47(p22)</sup>*

*"Every once in a while I think, 'hey, I'm lucky I have Parkinson's', I have friends who have had lung problems, who have had heart attacks, total loss of vision and are buried. We are alive"<sup>58(p41)</sup>*

**Synthesized finding 3.0:**

*Participation in PA is highly individual, with participants valuing activities which are perceived as personally relevant and tailored to their needs and preferences. Participant perceptions of PA are affected by expectations and self-evaluation of progress.*

This synthesized finding was derived from nine findings grouped into two categories

**Category 3.1: Participation in physical activity is affected by disease presentation and is highly individual**

People with Parkinson's highlighted that the highly individualized nature of the disease led to them undertaking PA that was specific to their unique circumstances. Participants noted that their participation in PA was influenced by their personality traits: resilience, need for independence, determination and a sense of humor. Equally while the nature of the disease was individualized, so were the coping strategies for that individual.

*"With this disease you have similarities, you know they are just similar and at other times it's like your disease is custom made to you".<sup>58(p40)</sup>*

**Category 3.2: Participants report individual preferences for the setting for physical activity. Tailored goals and self-evaluation of progress are important considerations for their engagement.**

The location was considered important for the participants, with some preferring home and others a hospital or community setting. Whatever the setting, participants were eager that goals were tailored to their needs. Participants' expectations and self-evaluation of the PA program were often different from their instructor viewpoint.

*"The commitment to the program will be better if it is at the hospital and under the supervision of a therapist. At home, you may get busy with other stuff; defer the exercises and end- up not doing them." <sup>57 (p514)</sup>*

*"I tend to exercise at home rather than going to the gym because it fits in with my lifestyle really. At the weekend I have my granddaughter and also I am working three times a week."  
<sup>56(p922)</sup>*

*"I believe that at my stage of Parkinson's progress that I have to be concerned about power and balance." <sup>45(p6)</sup>*

**Synthesized finding 4.0:**

*External factors can affect participants' experience of PA. Involvement of family members/ friends and use of music make sessions enjoyable and increase wellbeing. Support from instructors to ensure PA programs are structured and simple to undertake, to explain the relevance of activities and to facilitate progression give participants' confidence and enhances their participation.*

This finding was comprised of 11 findings and three categories.

**Category 4.1: Reassurance and support from group members, instructor, partner or family are important for participation in physical activity, while the use of music enhances enjoyment**

People with Parkinson's disease felt that an important aspect of group PA programs was the sense of humor and optimism from all members of the group and that a qualified instructor who was knowledgeable about the disease was a source of support and reassurance. Music as part of the program helped with movement and enjoyment.

*"The dance made me feel more graceful, moving and flowing with the music, it made me feel that I had to move when the music started."* 47(p19)

*"I wouldn't have liked, I wouldn't have gone if [husband] hadn't have been my partner I don't think. I liked that very much, I liked it a lot."* 54(p3)

*"A few people started off better than me... and that bothered me. But the instructor told me not to worry about it and that I should work at my own pace. I didn't think I could do it. I nearly gave up. But the leader always insisted that I could do it, so I had to prove myself and then I could."* 5(p180)

**Category 4.2 Supervision from an instructor who can provide education on the benefits of exercise as well as prescribe and progress exercises enhances participation.**

Participants felt that an important influence on their participation was the supervision while they were undertaking the exercise program as well as the education given by the instructor in terms of the relevance and usefulness of the exercises. Furthermore, it was important that the exercise program was both challenging and progressive.

*"For the first time ever I felt that someone was truly taking care of me that was the best piece of the intervention. It made me feel in turn that I should take care of myself by committing to the exercise program. The therapist was an excellent motivator."* 61(p25)

*"I think it should be clear how the exercises fit into the program. That's helpful. If I feel that the exercises make a difference, then I can do them more. Also having the general idea of the benefits of doing the exercise. I think the exercise is good for me and by doing the exercise I appreciate that there is a difference."* 56(p923)

**Category 4.3: Simplicity of exercise program:**

Participants felt that having a simple exercise program enhanced participation both in class but also when they were completing exercises at home. A perceived lack of clarity or relevance of the exercise program was considered to inhibit participation.

*“The DVD was simple and easy to follow its use at home was a strong motivator to continue doing the exercises.”* <sup>61(p25)</sup>

*“Sessions with physiotherapy actually taking me through with the exercises; that is good I think. They gave me exercises to do at home but I have not continued using them because of a couple of things actually. For back exercises there was no standard to do them. So, you do a lot and a lot of exercises like the hand behind the shoulder or the hand in front but actually you do not know what for the exercises are and the differences are tricky . . . I think exercises should be simple and clear how they fit into the program. That’s helpful”.* <sup>56(p923)</sup>

## **Objective 2: Explore pwPD perceptions of barriers and enablers to physical activity**

### **Synthesized finding 5.0:**

*A personal desire to maintain independence and a belief that PA can slow deterioration are driving forces for participation. Motivation is enhanced by perceived improvement in symptoms and feelings of accountability to oneself or others.*

This synthesized finding was comprised of 12 findings and three categories.

### **Category 5.1 Perceived improvement in wellbeing and physical ability aids motivation to participate in physical activity**

Participants identified that if they perceived an improvement in their performance, whether this was physical or psychological, that this aided their desire to continue to participate in the PA program.

*“The exercise program has affected me both mentally and physically before I got to know you and was introduced to this program I used to lock myself away at home fear of falling was a big issue. I was therefore not moving ... Now my mobility has improved dramatically ... I feel as if I have regained big chunk of my life”* <sup>61(p25)</sup>

*“My health is my priority and if exercise would help then I will exercise daily. I really would like to reach that level of doing things by my own and not relying on others; this is all what I want.”* <sup>57(p515)</sup>

### **Category 5.2: Personal desire to maintain function and/or slow progression of symptoms is a key motivator for continued participation in physical activity**

Participants perceived that undertaking PA could slow down and/or control the progression of the disease as well as ameliorate the disease symptoms associated with it. Moreover, PA was viewed by participants as a way of maintaining a self-image of themselves as an active and independent person.



*“And... then it's my goal to try to keep myself ...keep myself on the go as long as possible so that I ... yes, to be part of life. Not only to sit on a park-bench and... hear somebody talk ... but... to be active as well as I can.” 44(p2241)*

*“I have no other answers with this, with this disease... it's something I want to try and fight... and I don't know how to fight it [pause]. I don't want to be overmedicated. I'm hoping exercise can flat line it or slow down the progression or help me. I don't know. So it's mainly my decision to [participate in physical activity].” 30(p1933)*

### **Category 5.3: Personal obligation to oneself and to supportive others ensures a commitment to exercise.**

Participants expressed a view of personal accountability for maintaining their health and wellbeing. This was reinforced by education on the benefits of PA, which was provided by instructors. This obligation was enhanced further by commitment to undertake PA with a supportive other, such as an instructor.

*“I think having a commitment to meet someone at a specific planned time was most important. Let's face it; what I really felt like doing some mornings was to stay in bed! It would have been easy to make excuses to myself if I did not know I had to meet you.” 52(p120)*

*“One tried to do (exercise) as well as one can in everything and... doesn't try to waste time in any way but tries to do as well as possible... because the doctor said that.. exercise is very important for everybody... for everybody who has Parkinson's disease... so I mustn't become an idler so...out and...yes walk a lot with poles to keep up the agility in arms and shoulders.”*

*44(p2241)*

### **Synthesized finding 6.0.**

*Participants report that personal characteristics such as exercise habit, information seeking, resilience, problem solving and interest in the activity are motivators for engagement. However, lack of time, low outcomes expectations and cultural challenges are seen as barriers. Comparisons with others can be a motivator or barrier to engagement*

This synthesized finding was derived from 12 findings and three categories

### **Category 6.1: Favorable or unfavorable comparison with others can be a motivator or barrier to engagement.**

People with Parkinson's identified that they made comparisons with others in the group based on age, disease severity and concomitant ability. These comparisons could be both beneficial and detrimental. For some people comparisons with others in the group aided motivation, to match fellow group member's level of function. However where comparisons were less favorable, with the group in terms of age, and disease severity, this could be a barrier to engagement.

*"That was an incentive for me to put more into it because I could see that one guy in particular was benefitting from it."* 45(p6)

*"I went a couple times but they're all, I hate to say it, quite elderly and that for me personally is very depressing . . . They're all a lot worse because they've had it longer so they're very few young people . . . So, we went to the social group but it's like being at a seniors' center . . . so I haven't gone after. . . It is really depressing to see what you have to look forward to becoming."* 30(p1932)

### **Category 6.2: Motivation for participation is influenced by personal characteristics.**

Participants identified a number of personal traits or characteristics that promoted engagement in PA. These included previous positive experience of PA, ability to problem solve, resilience and self-advocacy. Participants were eager to maintain their role in life and to be viewed as a valuable member of society.

*"...one was out running and doing aerobics and... such things. I used to participate in those gymnastic displays we had at that time... and that was fun...of course that was a driving force... (...) and there the habit too... (to exercise)."* 44(p2240)

*"Unless you are lucky enough to have a nurse practitioner like - --- or you find a good physical therapist, you have to be an advocate, you have to say 'I want physical therapy, what can you write me a prescription for? I want to go and be evaluated about how to use a car or I want to learn about how to get my oxygen better'... so I feel that you have to gather information, you have to be an advocate and tell them what you want and hope that you have a good circle of family and friends".* 58(p42)

*"It is typically a matter of identifying the right exercises on each occasion to alleviate the various neuro-muscular afflictions. For my shoulder I noted during the classes that the 'lasso, arrow and sword' provided some temporary relief – so, I used a similar routine at home to improve mobility and it seems to work better than anything else I have tried (e.g. stretching and strengthening)."* 47(p26)

### **Category 6.3: Barriers to participation in PA include a lack of outcome expectation, lack of time and cultural challenges.**

Participants identified a number of personal factors that influenced participation in PA, such as a lack of time due to work and or family commitments, and a belief by some individuals that they were active enough. As reflected in the second quote, participants living in Jordan reported specific cultural challenges, in that older people are not expected to be physically active in Arabic countries.

*"I feel I am physically better than other people... and the nature of my work requires a lot of movements. I work as a plumber; hence I move all the time."* 61(p25.)

*"At home [Jordan] I have the fear that my sons will comment on this. I am trying to avoid this. I did though all the sessions with the therapist in the clinic but did not do the sessions at home."* 61(p25)

### **Synthesized finding 7.0:**

*Difficulty obtaining an initial diagnosis, accessibility of services, disease symptoms (both physical and psychological) and severity all impact on pwPD's ability and desire to undertake PA.*

This synthesized finding was comprised of 15 findings and two categories.

### **Category 7.1: Both mental and physical disease specific symptoms are barriers to participation in physical activity**

Participants with Parkinson's disease identified disease specific barriers such as, stiffness, bradykinesia, fatigue and depression influenced their motivation and ability to take part in regular exercise programs.

*"Having the disease does influence my ability to exercise, because I think it is hard to concentrate. So focusing is difficult and also the tiredness and fatigue is another problem."* 56(p922)

*"Since I've been diagnosed with PD and I felt low...I became less motivated to do anything in life ... even when you invited me to do the exercises I felt apathetic"* 61(p26)

*"You've got to battle with willpower all the time."* 45(p5)

### **Category 7.2: Participants identify difficulty gaining a diagnosis as well as lack of referrals to physiotherapy, lack of information about the benefits of exercise which are compounded by a lack of services, and problems with access, as barriers to participation**

Participants identified that gaining a diagnosis of Parkinson's disease took a significant amount of time and was not always straightforward due to the insidious nature of the disease symptoms. Those in the early stages of Parkinson's disease were not eager to embrace the diagnosis of a neurological disease. Participants noted that information with regard to the benefits of PA was not generally discussed by the neurologist, nor were they referred to physiotherapy for advice and management of their condition. Participants reported a number of challenges with regard to access and availability of facilities that were suitable for their needs. These ranged from financial issues to physically getting to the facility and the accessibility of the environment once there.

*"I started to feel symptoms 6 years ago but I have only been diagnosed 2 years later. I was*

*complaining of general slowness of movement and fatigue; simple things would become difficult. The GP excluded PD as it did not fit with my age category, However I doubted it was PD, as the symptoms were similar to my father's, who is also a PD patient. When other symptoms started to appear like tremor, the GP decided to refer me to a specialized neurologist."* 57(p512)

*"[My] GP really didn't say much. Actually, neither doctor really encouraged [physical activity]. They didn't discourage it, but they didn't really come out and say, 'You should join this,' or 'You should do that.' There's probably a little bit more work that could be done there to keep people active."* 30 (pg 1931)

*"I had not any advice as to exercises. We picked up some leaflets at one time in the doctor's surgery, from the PD society, but I don't think there was anything in there that referred to specific exercises or something that was relevant to me".* 56 (pg922)

*"As you know I come from a distance and my participation would have been impossible without covering the transportation costs that was really important aspect."* 61(p25.)

### **Objective 3: Identify, from the perspective of pwPD, the impact of support mechanisms and behavior change interventions in maintaining participation in physical activity.**

#### **Synthesized finding 8.0:**

*Participants report group members, family, friends, and co-workers provide support for them to initiate and sustain PA.*

This synthesized finding comprised of 13 findings and three categories.

#### **Category 8.1 Group physical activity offers a positive communal experience and provides opportunities for socialization, support and confidence building.**

Participants identified significant social and emotional benefits of participating in group PA. Group attendance kept away feelings of isolation and depression as the participants had a common purpose. Participants valued the experience of exercising with others who had PD and with whom they felt a shared experience. Over time, they were able to build a good rapport with each other and were encouraged by seeing improvements in group members' abilities. Participants identified that groups offered the opportunity to support each other and provide advice with regards to their problems. This included learning about the disease from each other and communal problem solving.

*"When you get a Parkinson's diagnosis, [you] tend to back into a cage somewhere where nobody can see my weaknesses. You tend to exclude yourself from society. When you join something like Dancing with Parkinson's you become part of a larger group and it's much easier to fight that weakness.... The other classmates are a benefit that I didn't expect or think*

*about at the time.*" 59(p3)

*"I didn't know anyone with Parkinson's before I came to these classes. I was all alone. It's not just about dancing, it's making friends and sharing."* 47(p27)

*"Very positive communal experience; pleased to see improvements in others."* 55(p1266)

*"[We] exchanged thoughts and notes that we had we all seem to have been on the Internet at various stages, gathering information, and it was very helpful."* 46(p1355)

### **Category 8.2. Family support and encouragement to initiate and sustain physical activity**

Participants identified that family support was an important element, which encouraged uptake and engagement in PA. Family support included encouragement and partaking in the PA with them.

*"Family has always been a source of support for me to accept the disease and to deal with it. A lot of mornings I would be very tired sitting on my sofa or lying in my bed until my son comes and asks me to go for a walk with him. His encouragement pulls me up and it's just about the start that is difficult then I get clicked on; I usually feel much better afterwards."* 57(p515)

*"They encourage me, goad me, embarrass me into doing some [activities] and they also will alter their activities to accommodate me which is very good. [My husband] just you know, like he always is trying to get me into doing more. He probably encourages me and gets me going more than I would do myself."* 30(p1929)

### **Category 8.3 Support and encouragement from friends and co-workers**

Participants reported that friends offered instrumental support in terms of provision of transport and mutual participation in PA. Co-workers were also supportive, for example organizing workload to allow the participants' time to attend PA programs.

*"They'll come out and walk with me sometimes or friends will come out and bike with me . . . it's nice to have friends who are compassionate and ah understand what you are going through."* 57(p1930)

*"They were all very supportive because I started [exercising at the research center] when I was still working. So they all made sure, no matter who was working with me that I got off in time."* 30(p1930)

## **Discussion**

### **Summary of findings**

The purpose of this qualitative systematic review was to synthesize the best available evidence of pwPD experiences and preferences for PA, their perceived enablers and barriers to engagement, as well as pwPD views of support mechanism and behavior change interventions designed to sustain participation. A comprehensive search of the literature yielded 21 studies that met the inclusion criteria. The studies involved both men and women with a diagnosis of PD from a variety of countries and provided data from studies, which used various qualitative and mixed method designs. There was a range of methodological quality of the included studies which ranged from over 70% in 16 studies and over 50% in four studies with one study achieving 30% on the JBI criteria for critical appraisal.<sup>40</sup> During data extraction, a decision was taken to exclude two studies<sup>41,42</sup> from further synthesis as they did not provide any illustrations of the participant voice to support their findings. The remaining 19 studies resulted in 105 findings, which were grouped in to 20 categories and aggregated into eight synthesized findings.

The review identified that pwPD viewed PA as an enjoyable and positive experience, which could aid control of their symptoms and enhanced their quality of life. However, participation in PA was a challenge due to the individualized, progressive and fluctuating nature of the disease that was often further complicated by medication cycles. Despite these challenges, pwPD identified personal coping strategies to allow them to undertake functional tasks and engage in PA. This review identified a number of contributory factors that influenced pwPD's ability to participate in PA. These factors can be categorized into intrapersonal characteristics such as; self-efficacy, beliefs and motivation to undertake PA, program design; setting, choice of activities, which were supervised by a knowledgeable instructor who could offer support in terms of monitoring, supervising, educating, and prescribing and progressing individually tailored programs; this enhanced their confidence.

Participants wished to take part in a program that they found enjoyable and groups were viewed positively where they were inclusive of various PA levels and where people perceived connections between themselves and other participants (for instance similarities in age or disease severity). Group cohesiveness also contributed to a sense of belonging and a social connection, which was important for sharing information and experiences and aided engagement. Regular participation in the activity gave pwPD a sense of achievement, which improved their wellbeing. Environmental factors including the accessibility of PA programs in terms of locality and public transport routes, and external support from family, friends and coworkers were also significant contributory factors for participation.

### **Discussion of findings in relation to contemporary literature**

These qualitative findings provide an insight into the views and experiences of pwPD, and complement available quantitative evidence of effectiveness, to support the development of complex interventions to improve health.<sup>62</sup> Physical activity behavior is a multifaceted construct and has proven challenging to promote in older people,<sup>63,64</sup> long-term conditions,<sup>65-67</sup> and those with PD,<sup>9,11,68</sup> despite the fact that there is a wealth of quantitative evidence which identifies the benefits of PA in pwPD.<sup>13-17</sup> There are likely a number of contributory factors which influence participation, and this review adds a comprehensive qualitative overview of the experiences and preferences of those people with PD who

do engage in PA.

The personal characteristics associated with ongoing engagement highlighted in our review have resonance with those described within the self-efficacy literature. Bandura defines self-efficacy as the 'belief in the ability to exercise control over one's health habits'.<sup>69(p144)</sup> Individuals with high self-efficacy expect more favorable physical, social and self-evaluative outcomes, view impediments as more manageable, and set higher goals for themselves.<sup>69</sup> The findings of this review would suggest that pwPD who engage in PA demonstrate high personal self-efficacy in overcoming barriers to participation with the use of individualized coping strategies. In accordance with this review, self-efficacy has shown to be a determinate of PA behavior in pwPD.<sup>70</sup>

However, a problem with the utilization of behavioral change theories, such as Bandura's social cognitive theory, in pwPD is that the development of coping strategies to overcome impediments and/or barriers to PA is likely to require a significant amount of reasoning and cognitive capacity that those participants where cognitive function has deteriorated, may not be able to initiate.<sup>4,71</sup>

A further finding from this review is that pwPD's motivation to undertake PA is dependent on whether the activity meets their goals and whether there is a sufficient level of challenge in the activity and this is reflected in the variety of PA undertaken by pwPD. The important role of motivation in influencing behavior is outlined by the theory of self-determination.<sup>72</sup> Self-determination theory focusses on the processes through which a person acquires the motivation for initiating new health related behaviors and maintaining them over time. The theory assumes that individuals by nature are active and self-motivated but that they can also be alienated or disaffected by unfavorable social contexts. The balance between their inherent active nature and the social environment can either support or impede that nature.<sup>73</sup> Human behavior is based on the desire for autonomy, in terms of personal endorsement, competence, in terms of the need to feel challenged but capable of achieving goals, and relatedness reflects the degree to which an individual feels connected to and understood by others.<sup>72</sup>

Participation in PA is a multifaceted construct and the findings from this review identified the role of the affective domain as a contributory factor for participation. People with Parkinson's disease expressed a preference for an activity that was both fun and enjoyable. The affective domain is posited as an alternative model for enhancing motivation and adherence in PA.<sup>74,75</sup> For example intrinsic regulation (behavioral engagement for reasons of pleasure) and affective attitude (expectations of enjoyment, fun, pleasure) have shown positive effects on PA in older adults.<sup>75</sup> Enjoying an activity and feeling good about participating may re-enforce that behavior, which is an important aspect for sustained engagement. Previous positive experience of PA enhanced pwPD views of engagement in PA.<sup>76</sup> Anticipation that PA will not be enjoyable and or unpleasant may explain why some pwPD are sedentary.

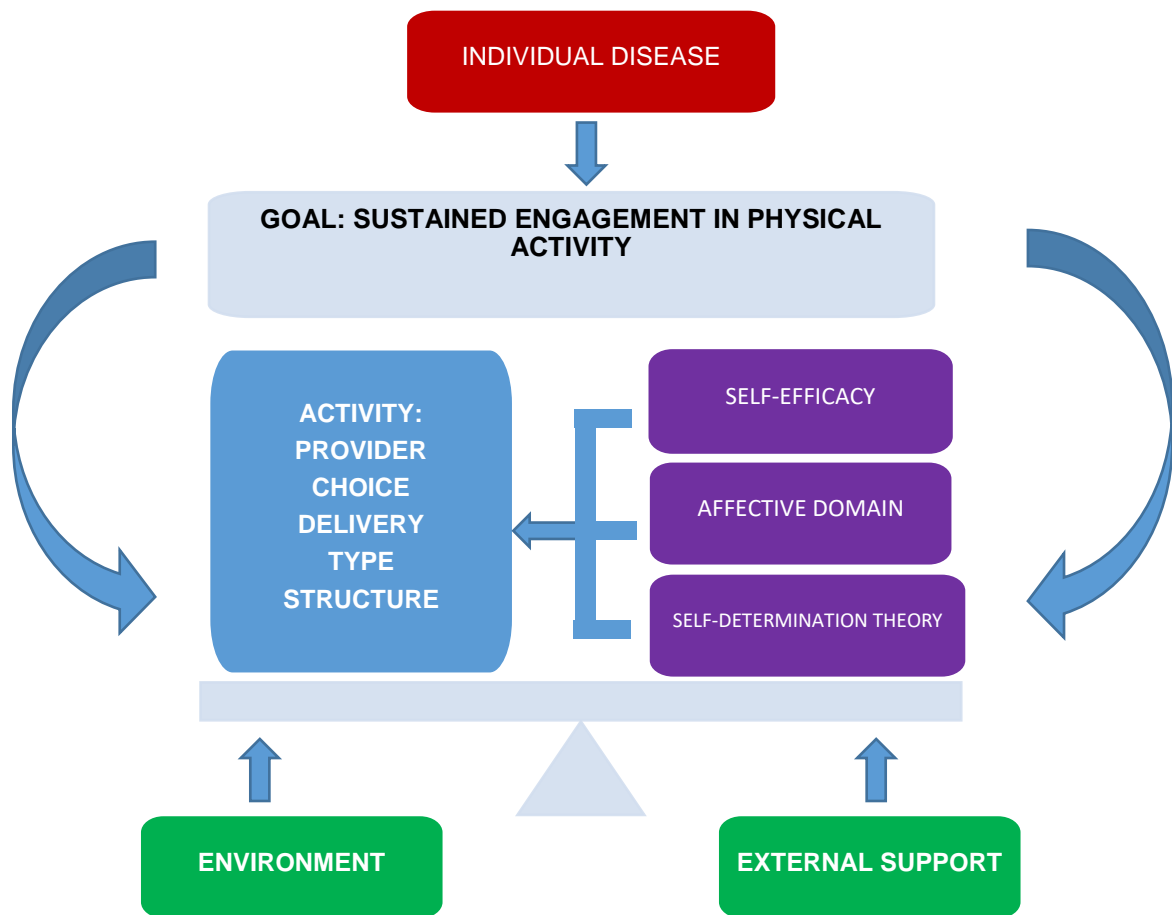
This review provided evidence that support from peers, family, and friends and in particular, the instructor were important factors in aiding motivation to attend PA programs. Support was provided in terms of instrumental, e.g. providing transport and mutual participation, emotional e.g. providing encouragement and informational, e.g. education about exercise.<sup>30</sup> Furthermore, accessibility in terms of public transport, cost and access were contributing factors influencing engagement and sustained

participation. These findings are in agreement with research in older people<sup>64</sup> and people with disabilities and/or long-term conditions.<sup>65,67,77,78</sup>

This review suggests that a range of factors including disease presentation, intrapersonal characteristics, program design, social and physical environment and external support all contribute to sustained engagement in PA in pwPD. As PA in pwPD is affected by a diverse number of factors the integration of ideas from several behavioral theories and models has been incorporated into a proposed ecological model of sustained engagement in PA. This model takes in account the different contributory factors and the importance of the relationship between individuals and their social and physical environment.<sup>73,79</sup> See Figure 2. What this review is not able to determine is the relative importance of these factors, or combination of factors that contribute the most to a person with PD's ability to participate in PA. This picture is further complicated by the individualized and fluctuating nature of the disease presentation and the impact of on/off symptoms due to medication cycles, which need to be considered by pwPD who are planning PA. Therefore, it is likely that these factors are not static but fluctuate on a day-to-day basis adding to the complexity of engagement and sustained participation.



**Figure 2: Proposed ecological model of people with Parkinson's disease engagement in physical activity**



### Limitations of the review

A limitation of this review is that we did not find any studies that described pwPD views and experiences of specific behavior change interventions. It may be that instructors were encouraging behavior change implicitly within the program but that this was not necessarily perceived by pwPD as a strategy. Regardless, the fact that it was not mentioned suggests that it was not prioritized as important by participants.

The studies comprising this review are confined to Western countries with the exception of two studies, which were undertaken in Jordan and provided the information with regards to the cultural challenges of PA in older people in an Arabic country. None of the included studies identified the cultural make up of participants, which means the impact of culture, and ethnicity on PA in pwPD was not able to be fully explored.

The research evidence with regard to pwPD's; experiences, preferences, and motivators and barriers to PA as well as strategies designed to enhance participation is limited by the small number of included studies and small participant numbers. Furthermore, the ConQual assessment for the findings is low. Therefore, any recommendations arising from the review are also lowered in their applicability.

Importantly, what this review does not address are the views and experience of pwPD who are inactive, or who have discontinued their engagement in PA, as all studies involved pwPD who were active. Therefore, the synthesized findings are limited to pwPD who undertake PA, rather than those who do not engage. Given that those who do not choose to engage are the individuals who may need the most support to do so, this is a significant limitation in the existing evidence base.

### Conclusion:

People with PD perceive engagement in PA as a positive experience, which aids with managing their symptoms and enhancing their wellbeing and quality of life. This review identified a number of contributory factors, which influenced pwPD's ability to sustain engagement in PA: disease presentation, intrapersonal characteristics, program design, external support and the social and physical environment. The contribution and weighting of these factors will affect an individual's engagement and sustained participation in PA.

### Recommendations for practice

The recommendations for practice are graded according to the JBI Grades of Recommendations,<sup>80</sup>

People with Parkinson's disease value the following aspects as important in sustaining their engagement in PA

1. A choice of PA programs that are meaningful and that meet their needs. Group programs that were inclusive of abilities, but also challenging were viewed positively. The incorporation of individually tailored goals would allow participants to evaluate their progress and should be related to their functional activities. (Grade B)

2. The PA program should be overseen by an instructor who is knowledgeable about Parkinson's disease. (Grade B)
3. Programs that are enjoyable: with a positive and inclusive social environment and the use of music. (Grade B)

#### **Recommendations for policy**

1. The involvement of pwPD in the design and commissioning of PA programs to ensure that their needs are understood and met. (Grade B)
2. People with Parkinson's disease value PA irrespective of provider and therefore policy makers should collaborate with the third sector to encourage the delivery of PA programs. Referrals and signposting to local groups should reflect this in order to offer choice and increase accessibility locally. (Grade B)
3. Policy makers should recognize the importance of supporting PA through the provision of resources, such as education materials. (Grade B)

#### **Recommendations for research**

1. Authors should provide full information with regards to the methodology and philosophical underpinnings of the research in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ guidelines).<sup>81</sup>
2. Research should be carried out to explore the perspectives of pwPD who are inactive with the aim of exploring the similarities and differences to those who engage, with the intention of developing the proposed model further.
3. Research should be carried out with instructors to explore current practice, readiness and ability to support pwPD to engage in PA with the aim to explore what behavior change interventions they utilize within programs and their views in terms of their success in engaging pwPD in PA.

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  78. Slade SC, Molloy E, Keating JL. People with non-specific chronic low back pain who have participated in exercise programs have preferences about exercise: a qualitative study. *Australian Journal of Physiotherapy* 2009; 55(2): 115-121.
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## Appendices:

### Appendix Ia Dependability Scores for included studies

Dependability Score						
Citation	Is there congruity between the research methodology and the research question or objectives	Is there congruity between the research methodology and the methods used to collect data?	Is there congruity between the research methodology and the representation and analysis of data?	Is there a statement locating the researcher culturally or theoretically?	Is the influence of the researcher on the research, and vice-versa, addressed?	Dependability Score
Bassett, S. Stewart, J. Giddings, L. (2012) <sup>52</sup>	Yes	Yes	Yes	No	No	3/5 Mod
Bognar, S., Defaria, AM. O'Dywer, C et al (2017) <sup>59</sup>	Yes	Yes	Yes	No	No	3/5 Mod
Crizzle, AM., Newhouse, IJ. (2012) <sup>5</sup>	Yes	Yes	Yes	No	Yes	4/5 High
Davis, JT. Erbart, A. Trcinski, BH et al (2003) <sup>58</sup>	Yes	Yes	Yes	No	No	3/5 Mod
Erikson, BM. Arne, M. Ahlgren, C (2013) <sup>44</sup>	Yes	Yes	Yes	Yes	Yes	5/5 High
Hammarlund, CS. Anderson K. Anderson, M. et al (2014) <sup>48</sup>	Yes	Yes	Yes	No	Yes	4/5 High
Hislop, J. Gray, S. Melling, S. et al (2015) <sup>53</sup>	Yes	Yes	Unclear	No	No	2/5 Mod
Houston, S. McGill A. Lee, R. et al (2015) <sup>47</sup>	No	Yes	Unclear	No	No	1/5 Low
Jones, D. Rochester, L. Birleson, A. et al (2008) <sup>50</sup>	Yes	Yes	Yes	Yes	Yes	5/5 High
Khalil, H. Busse, M. Quin, L et al (2017) <sup>61</sup>	Yes	Yes	Yes	No	No	3/5 Mod
Khalil, H. Nazzal, M. Al-Sheyab, N. (2016) <sup>57</sup>	Yes	Yes	Yes	No	No	3/5 Mod
Kunkel, D. Robinson, J. Fitton, C et al (2017) <sup>54</sup>	Yes	Yes	Yes	Yes	No	4/5 High
O'Brien, C. Clemson, L. Caning CG.	Yes	Yes	Yes	No	Yes	4/5 High



(2016) <sup>45</sup>						
O'Brien, M. Dodd, KJ. Bilney, B (2008) <sup>46</sup>	Yes	Yes	Yes	Yes	No	4/5 High
Pretzer-Aboff, I. Galik, E. Resnick B. (2009) <sup>51</sup>	Yes	Yes	Yes	No	No	3/5 Mod
Quinn, L. Busse, M. Khalil H. et al (2010) <sup>56</sup>	Yes	Yes	Yes	No	No	3/5 Mod
Ravanek, MJ. Schneider MA. (2009) <sup>30</sup> ,	Yes	Yes	Yes	No	No	3/5 Mod
Sheehy, TL. (2014) <sup>49</sup>	Yes	Yes	Yes	Yes	No	4/5 High
Westheimer, O. Mcrae, C Henchcliffe, C et al (2015) <sup>55</sup>	Yes	Yes	Yes	No	No	3/5 Mod

## Appendix Ib: Calculation of ConQual Score

<b>Synthesized finding 1:</b> Participating in PA is seen as positive, participants report improvements in physical and psychological function and symptom control. Participating in PA leads to holistic changes, including a sense of achievement, improved confidence and wellbeing.		
<b>Dependability</b> Crizzle et al (2012) (H) Hammarlund et al (2014) (H) O'Brien et al (2008) (H) Sheehey (2014) (H) Bassett et al (2012) (M) Bognar et al (2016) (M) Westheimer et al (2015) (M) Houston et al (2015) (L)  Dependability is moderate: downgraded 1 level due to a mixture of dependability among findings (4 high, 3 moderate, 1 low)	<b>Credibility</b> 13 findings, 2 categories 12 Unequivocal 1 Credible  Credibility of findings is moderate: downgraded 1 level due to a mixture of unequivocal and credible findings	<b>ConQual Score</b>  Confidence in the findings is low: downgraded 2 levels due to moderate dependability and moderate credibility
<b>Synthesized finding 2:</b> Parkinson's disease is perceived to impact on all aspects of PA with temporal fluctuation in symptoms presenting both emotional and physical challenges. Changes to the level and type of PA and the use of individual strategies is used to maximize participation.		
<b>Dependability</b> Hammarlund et al (2014) (H) Jones et al (2008) (H) Kunkel et al (2017) (H) O'Brien et al (2016) (H) Davis et al (2003) (M) Pretzer Aboff et al (2009) (M) Houston et al (2015) (L)  Dependability is moderate: downgraded 1 level due to a mixture of dependability (4 high, 2 moderate, 1 low)	<b>Credibility</b> 20 findings, 2 categories 17 Unequivocal 3 Credible  Credibility of findings is moderate: downgraded 1 level due to a mixture of unequivocal and credible	<b>ConQual Score</b>  Confidence in the findings is low: downgraded 2 levels due to moderate dependability and moderate credibility
<b>Synthesized finding 3:</b> Participation in PA is highly individual, with participants valuing activities, which are perceived as personally relevant, and tailored to their needs and preferences. Participant perceptions of PA are affected by expectations and self-evaluation of progress.		
<b>Dependability</b> Erickson et al (2013) (H) O'Brien et al (2008) (H) O'Brien et al (2016) (H) Davis et al (2003) (M) Khalil et al (2016) (M) Pretzer Aboff et al (2009) (M) Quinn et al (2010) (M) Houston et al (2015) (L)  Dependability is moderate: downgraded 1 level due to a	<b>Credibility</b> 9 findings, 2 categories 5 Unequivocal 4 Credible  Credibility of findings is moderate: downgraded 1 level due to a mixture of unequivocal and credible	<b>ConQual Score</b>  Confidence in the findings is low: downgraded 2 levels due to moderate dependability and moderate credibility

mixture of dependability ( 3 high, 4 moderate, 2 low)		
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**Synthesized Finding 4:** External factors can affect participants' experience of PA. Involvement of family members/ friends and use of music made sessions enjoyable and increases wellbeing. Support from instructors to ensure PA programs are structured and simple to undertake, to explain the relevance of activities and to support progression give participants' confidence and enhances their participation.

<b>Dependability</b>	<b>Credibility</b>	<b>ConQual score</b>
Crizzle et al (2012) (H) Kunkel et al (2017) (H) Bassett et al (2012) (M) Kahlil et al (2017) (M) Pretzer Aboff et al (2009) (M) Ravanek et al (2009) (M) Houston et al (2015) (L) Quinn et al (2010) (L)  Dependability is moderate: downgraded 1 level due to a mixture of dependability (2 high, 4 moderate, 2 low)	11 findings 3 categories 8 Unequivocal 3 Credible  Credibility of findings is low: downgraded 1 level due to a mixture of unequivocal and credible.	Confidence in the findings is low: downgraded 2 levels due to moderate dependability and moderate credibility.

**Synthesized finding 5:** A personal desire to maintain independence and a belief that physical activity can slow deterioration are driving forces for participation. Motivation is enhanced by perceived improvement in symptoms and feelings of accountability to oneself or others.

<b>Dependability</b>	<b>Credibility</b>	<b>ConQual Score</b>
Erikson et al (2013) (H) O'Brien et al (2016) (H) Bassett et al (2012) (M) Bognar et al (2016) (M) Khalil et al (2017) (M) Quinn et al (2010) (M) Ravanek et al (2009) (M)  Dependability is moderate: downgraded 1 level due to a mixture of dependability (2 high, 5 moderate)	12 findings 3 categories 7 Unequivocal 5 Credible  Credibility of findings is low: downgraded 1 level due to a mixture of unequivocal and credible.	Confidence in the findings is low: downgraded 2 levels due to moderate dependability and moderate credibility.

**Synthesized finding 6:** Participants report that personal characteristics such as exercise habit, information seeking, resilience, problem solving and interest in the activity are motivators for engagement. However, lack of time, low outcomes expectations and cultural challenges are seen as barriers. Comparisons with others can be a motivator or barrier to engagement

<b>Dependability</b> Erikson et al (2013) (H) Kunkel et al (2017) (H) O'Brien et al (2016) (H) Sheehy (2014) (H) Bognar et al (2016) (M) Davis et al (2003) (M) Khalil et al (2017) (M) Ravanek et al (2009) (M) Houston et al (2015) (L)  Dependability is moderate: downgraded 1 level due to a mixture of dependability (4 high, 4 moderate, 1 low)	<b>Credibility</b> 12 findings 3 categories 10 Unequivocal 2 Credible  Credibility of findings is moderate: downgraded 1 level due to a mixture of unequivocal and credible.	<b>ConQual Score</b>  Confidence in the findings is low: downgraded 2 levels due to moderate dependability and moderate credibility.
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**Synthesized finding 7:** Difficulty obtaining an initial diagnosis, accessibility of services, disease symptoms (both physical and psychological) and severity all affect pwPD's ability and desire to undertake physical activity.

<b>Dependability</b> O'Brien et al (2016) (H) Sheehy (2014) (H) Davis et al (2003) (M) Khalil et al (2016) (M) Khalil et al (2017) (M) Pretzer Aboff et al (2009) (M) Quinn et al (2010) (M) Ravanek et al (2009) (M)  Dependability is moderate: downgraded 1 level due to a mixture of dependability (2 high, 6 moderate)	<b>Credibility</b> 15 findings 2 categories 14 Unequivocal 1 Credible  Credibility of findings is moderate: downgraded 1 level due to a mixture of unequivocal and credible.	<b>ConQual Score</b>  Confidence in the findings is low: downgraded 2 levels due to moderate dependability and moderate credibility.
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**Synthesized finding 8:** Participants report group members, family, friends, and co-workers provide support for them to initiate and sustain physical activity

<b>Dependability</b> Crizzle et al (2012) (H) O'Brien et al (2008) (H) O'Brien et al (2016) (H) Sheehy (2014) (H) Bognar et al (2016) (M) Hislop et al (2015) (M) Khalil et al (2016) (M) Kahlil et al (2017) (M) Ravenek et al (2009) (M) Houston et al (2016) (L)  Dependability is moderate: downgraded 1 level due to a mixture of dependability (4 high, 5 moderate, 1 low).	<b>Credibility</b> 13 findings 3 categories 10 Unequivocal 3 Credible  Credibility of findings is moderate: downgraded 1 level due to a mixture of mainly unequivocal and credible.	<b>ConQual Score</b>  Confidence in the findings is low: downgraded 2 levels due to moderate dependability and moderate credibility.
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## Appendix II: Search Strategies

### Medline and Embase via OVID Search Strategy

	Conducted 29 June 2017
	Search term
#1	Parkinson*.ti,ab,kw. Or Parkinson's disease/ or exp Parkinson Disease/ or Parkinson*.mp. or exp Aged/ or pd.ti,ab,kw. Or exp Aged/ or exp Parkinson Disease/ or pd*.mp
#2	Physical activity.ti,ab,kw. or physical activity/ or exercise.ti,ab,kw. or exercise/ or motor activity.ti,ab,kw. or physical fitness*.ti,ab,kw. or leisure activity.ti,ab,kw. or walk*.ti,ab,kw. or tai chi.ti,ab,kw. or qigong.ti,ab,kw. or swim*.ti,ab,kw. or yoga.ti,ab,kw.
#3	Experience*.ti,ab,kw. or preference*.ti,ab,kw. or view*.ti,ab,kw. or exp Attitude to Health/ or exp Attitude/ or exp Health Knowledge, attitudes, Practice/ or view*.mp or exp Choice Behavior/ or preference*.mp. or exp Decision making/ or participation.ti,ab,kw. or engagement.ti,ab,kw. or adherence.ti,ab,kw. or compliance.ti,ab,kw. Or concordance.ti,ab,kw. or enablers.ti,ab,kw. or motivators.ti,ab,kw. or facilitators.ti,ab,kw.
#4	1 and 2 and 3
#5	Limit to English language and humans

### Amed and CINAHL via (EBSCO)

	Conducted 29 June 2017
Search ID	Search terms
S4	Parkinson's disease OR Parkinson* or PD (all text TX)
S15	Physical activity or exercise or exercise therapy or leisure time physical activity or walking or swimming or tai chi or qigong or yoga or motor activity (all text TX)
S18	Experiences or perceptions or attitudes or views or preference (all text TX)
S24	Participation or adherence or complain or concordance or engagement or involvement or participation or enablers or barriers or facilitators or factors or motivators (all text TX)
S25	S4 and S15 and S18 and S24 (limits English language) (Expanders – apply related words)

### Web of Science

	Conducted 29 June 2017
#1	TOPIC: (Parkinson's disease) OR (Parkinson*) or (PD) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-SSH, ESCI Timespan = All years
#2	TOPIC: (physical activity) OR TOPIC: (exercise) OR TOPIC: (physical fitness) OR TOPIC: (leisure activity) OR TOPIC: (walk*) OR TOPIC: (tai chi) OR TOPIC: (qigong) OR TOPIC: (yoga) OR TOPIC: (swim*) OR TOPIC: (motor activity) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years
#3	TOPIC: (experience*) OR TOPIC: (preference*) OR TOPIC: (attitude*) OR TOPIC: (view*) Indexes= SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years
#4	TOPIC: (participation) OR TOPIC: (engagement) OR TOPIC: (compliance) OR TOPIC: (concordance) OR TOPIC: (enablers) OR TOPIC: (motivators) OR TOPIC: (facilitators) OR TOPIC: (barriers) SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years
#5	#1 AND #2 AND #3 AND #4 SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years

## SCOPUS

	Conducted 29 June 2017
#1	"Parkinson's disease" (article title, abstract, keywords) AND "Physical activity" (article title, abstract, keywords) AND "experience" (article title, abstract, keywords)
#2	Limit Published all years to present

## Google and Mednar

	Conducted 30 June 2017
#1	Parkinson's disease physical activity experience
#2	"Parkinson's disease" and "physical activity" and "experience" and "participation"

## Conference Paper Index

	Conducted 30 June
#1	Parkinson's disease AND Physical activity AND Experience

## PQDT open

	Conducted 30 June 2017
#1	"Parkinson's disease" and "physical activity"

## Open Grey

	Conducted 30 June 2017
#1	Discipline 05* "Parkinson's disease" Limiter = English

## Appendix III: Excluded studies with reasons

Author(s)	Title	Exclusion reason
Afshari, M. Kianirad, Y. Bega, D. 2016	Motivators and barriers to participation in exercise in Parkinson's disease	No qualitative data
Onnalin Jandeaw, Priya Jagota, Surat Singmaneesakulchai, Nonglak Boonrod, Lalita Kaewwilai, et al 2014	Perception of the disease in patients with Parkinson's disease: past, present and future	Not phenomena of interest
Traeger B.E 2016	Identifying the Types of Physical Exercise that Help Individuals with Parkinson's disease manage their symptoms: A modified Delphi study	PD population is not identifiable
Benharoch, J. Wiseman, T. 2004	Participation in Occupations: Some Experiences of People with Parkinson's Disease	Not phenomenon of interest
Blandy, L. M. Beevers, W. A. Fitzmaurice, K. Morris, M. E 2015	Argentine tango dancing for people with mild Parkinson's disease: A feasibility study	No qualitative data
Duncan, R. P. Earhart, G. M. 2011	Measuring participation in individuals with Parkinson disease: relationships with disease severity, quality of life, and mobility	No qualitative data

Ellis, R. Kosma, M. Cardinal, B. J. Bauer, J. J. McCubbin, J. A. 2007	Physical activity beliefs and behavior of adults with physical disabilities	PD population not identifiable
Ellis, T. Boudreau, J. K. DeAngelis, T. Brown, L. E. Cavanaugh, J. T. Earhart, G. M. Ford, M. P. Foreman, K. B. Dibble, L. E. 2013	Barriers to exercise in people with Parkinson disease	No qualitative data
Ellis, T. Latham, N. K. DeAngelis, T. R. Thomas, C. A. Saint-Hilaire, M. Bickmore, T. W. 2013	Feasibility of a virtual exercise coach to promote walking in community-dwelling persons with Parkinson disease	No qualitative data
Englert, D. Hirsch, M. Sanjak, M. Russo, P. Quinlan, M. Crum, K. Iyer, S. 2013	Barriers to physical activity among adults with idiopathic Parkinson's disease (PD)	No qualitative data
Estivill, M. 1995	Therapeutic aspects of aerobic dance participation	Not PD population
Fujimoto, K. I. Murata, M. Hattori, N. Kondo, T. 2016	Patients' perspective on Parkinson disease therapies: Comparative results of large-scale surveys in 2008 and 2013 in Japan	Not in English – no translation available
Garretto, N. Arce, M. Arakaki, T. Abaroa, L. Frola, P. Oliveri, M. Moreno, C. R. Rabinovich, D. 2011	Argentine tango as therapy for Parkinson's disease (PD)	No qualitative data
Grosset, K. A. Grosset, D. G. 2005	Patient-perceived involvement and satisfaction in Parkinson's disease: Effect on therapy decisions and quality of life	No qualitative data
Hirsch M.A, Sanjay Sl., Englert D., and Sanjak M. 2011	Promoting exercise in Parkinson's disease through community-based participatory research	No qualitative data
Houston S., and McGill A 2013	A mixed methods study into ballet for people living with Parkinson's.	Later study published in 2015, which utilized same participants. Limited qualitative data presented
Jette, A. M. Keysor, J. Coster, W. Ni, P. Haley, S. 2005	Beyond function: predicting participation in a rehabilitation cohort	PD population not identifiable
Koch, S. C. Mergheim, K. Raeke, J. Machado, C. B. Riegner, E. Nolden, J. Diermayr, G. von Moreau, D. Hillecke, T. K. 2016	The Embodied Self in Parkinson's Disease: Feasibility of a Single Tango Intervention for Assessing Changes in Psychological Health Outcomes and Aesthetic Experience	Not phenomena of interest not qualitative

Lakes, K. D. Marvin, S. Rowley, J. San Nicolas, M. Arastoo, S. Viray, L. Orozco, A. Jurnak, F. 2016	Dancer perceptions of the cognitive, social, emotional, and physical benefits of modern styles of partnered dancing	Not PD population
Landers, M. R. Lopker, M. Newman, M. Gourlie, R. Sorensen, S. Vong, R. 2017	A Cross-sectional Analysis of the Characteristics of Individuals With Parkinson Disease Who Avoid Activities and Participation Due to Fear of Falling	Not qualitative data
Li, F. Harmer, P. Fisher, K. J. Xu, J. Fitzgerald, K. Vongjaturapat, N. 2007	Tai Chi-based exercise for older adults with Parkinson's disease: A pilot-program evaluation	Not qualitative data
Li, F. Harmer, P. Liu, Y. Eckstrom, E. Fitzgerald, K. Stock, R. Chou, L. S. 2014	A randomized controlled trial of patient-reported outcomes with tai chi exercise in Parkinson's disease	Not phenomena of interest / not qualitative
Liao, Y. C. Wu, Y. R. Tsao, L. I. Lin, H. R. 2013	The Experiences of Taiwanese Older Individuals at Different Stages of Parkinson Disease	Not phenomena of interest
Loprinzi, P. D. Darnell, T. Hager, K. Vidrine, J. I. 2015	Physical activity-related beliefs and discrepancies between beliefs and physical activity behavior for various chronic diseases	Not PD population
Lyons, K. E. Pahwa, R. 2007	Electronic motor function diary for patients with Parkinson's disease: a feasibility study	Not qualitative not phenomena of interest
Malone, L. A. Barfield, J. P. Brasher, J. D. 2012	Perceived benefits and barriers to exercise among persons with physical disabilities or chronic health conditions within action or maintenance stages of exercise	Not qualitative data not PD
McNeely, M. E. Duncan, R. P. Earhart, G. M. 2015	Impacts of dance on non-motor symptoms, participation, and quality of life in Parkinson disease and healthy older adults	Not qualitative data
Mulligan, H. Whitehead, L. C. Hale, L. A. Baxter, G. D. Thomas, D. 2012	Promoting physical activity for individuals with neurological disability: indications for practice	PD participants are not identifiable therefore exclude as not population
Natbony, L. R. Zimmer, A. Ivanko, L. S. Studenski, S. A. Jain, S. 2013	Perceptions of a Videogame-Based Dance Exercise Program Among Individuals with Parkinson's Disease	Not qualitative data
Newitt, R. Barnett, F. Crowe, M. 2016	Understanding factors that influence participation in physical activity among people with a neuro-musculoskeletal	PD participants are not identifiable therefore exclude as not Population



	condition: a review of qualitative studies	
O'Brien C., Canning C.G., and Clemson L. 2013	Parkinson's disease: The experience of exercise.	Poster presentation: based on full study which was included in systematic review. So duplicate data
O'Brien C. 2014	Exercise participation in Parkinson's disease: A qualitative study	Thesis results published in published paper so duplicate data set.
Pentecost, C. Taket, A. 2011	Understanding exercise uptake and adherence for people with chronic conditions: a new model demonstrating the importance of exercise identity, benefits of attending and support	Not PD population
Pickering, R. M. Fitton, C. Ballinger, C. Fazakarley, L. Ashburn, A. 2013	Self-reported adherence to a home-based exercise program among people with Parkinson's disease	No qualitative data
Shanahan, J. Bhriain, O. Morris, M. E. Volpe, D. Clifford, A. M. 2016	Irish set dancing classes for people with Parkinson's disease: The needs of participants and dance teachers	No qualitative data
Sjödahl Hammarlund, C. Nilsson, M. H. Hagell, P. 2012	Measuring outcomes in Parkinson's disease: a multi-perspective concept mapping study	Not phenomena of interest
Sorrell, J. M. 2017	Living with Parkinson's Disease	Narrative paper only
Speelman, Arlene D. van Nimwegen, Marlies Bloem, Bastiaan R. Munneke, Marten 2014	Evaluation of implementation of the ParkFit program: A multifaceted intervention aimed to promote physical activity in patients with Parkinson's disease	No qualitative data
Sunwoo, M. K. Lee, J. E. Hong, J. Y. Ye, B. S. Lee, H. S. Oh, J. S. Kim, J. S. Lee, P. H. Sohn, Y. H. 2017	Premorbid exercise engagement and motor reserve in Parkinson's disease	Not phenomena of interest / not qualitative
Takahashi, K. 2008	Behavior in Parkinson's disease as related to self-efficacy and outcome expectancy	Not enough information
Tan, D. Tan, C. Tan, E. K. Mahfooza, A. 2015	The lived experiences of community dwelling adults with Parkinson's disease towards exercise and participation in a rehabilitation trial	Not enough information
Worthen-Chaudhari, L. C. 2011	New Partnerships Between Dance and Neuroscience: Embedding the Arts for Neuro recovery	Narrative commentary only

#### Appendix IV: Characteristics of included studies for methodological review

Author/ year	Methodology / Method	Phenom interest	Participants Age gender	Sampling / Setting/ Geography/ culture	Conclusions/ Outcomes	Reviewer Notes
Bassett, S. Stewart, J. Giddings, L. (2012) <sup>52</sup>	Mixed methods (single case repeated measures of five six-week phases ABACA)  Face to face semi- structured interview Content Analysis	Experiences and effects of the two types of walking (Nordic and ordinary)	1 x 64 year old woman Time with illness: 11 years H & Y: 2.5	Convenience sample Community setting Interview location: not identified Geography: New Zealand Culture: Monoculture	Interview analysis revealed that the participant considered Nordic Walking more beneficial than ordinary walking; her general health improved, and she coped better with daily activities	Only one participant as a single case report. Qualitative information extracted from interview
Bognar, S., Defaria, AM. O'Dywer, C et al (2017) <sup>59</sup>	Qualitative descriptive design Individual semi- structured interviews Content analysis with an inductive analysis method	Experiences and perceptions of pwPD who attended a dance program.	Ten participants with a diagnosis of PD. 8 males / 2 women Mean age: not given Age range 60 – 75+ Time with illness: not obtained H&Y: not specified (all mobile +/- aid)	Convenience sample Community setting Interview location: not identified Geography: Canada Culture – not specified	Dancing with PD classes allow for re-development of the social self, which can increase sense of enjoyment in life. Dance programs provide opportunities for social interaction, non-verbal communication and self- improvement, re- establishing self-identify and a sense of usefulness.	Good description of dance class, which was taught by dance instructor. Participation in dance class varied from 6 months to 4 years. Contacted author for article.
Crizzle, AM., Newhouse, IJ. (2012) <sup>5</sup>	Qualitative methodology  Semi-structured focus group, with observation of behaviors and	Motivators and barriers to exercise adherence 1 week post hydrotherapy program	Four participants with PD. 2 men/ 2 women Mean age 75.8 (range 71 to 89) 4 caregivers (2 spouse, 1 daughter,	Sampling: convenience Setting: community Interview location: not specified	Main theme: Constant reassurance and encouragement needed from instructor motivated PD participants to continue. Motivation: exercising in a	Exercise program was hydrotherapy and participants exercised 3 times a week for 6 weeks. Focus groups included pwPD and their carers. However only information

	<p>facial expression.</p> <p>Moderator with no affiliation to project conducted the focus group</p> <p>Content Analysis</p>	completion	<p>1 son)</p> <p>Mean time since diagnosis: not given</p> <p>H&amp;Y: 2 (stage 3) 2 (stage 2)</p> <p>Mobility: 2 independent; 1 cane; 1 walker</p>	<p>Geography: Canada.</p> <p>Culture – not specified</p>	group environment with pwPD; tailored exercise program for both physical and psychological needs.	from pwPD extracted.
<p>Davis, JT. Erbart, A. Trcinski, BH et al (2003)<sup>58</sup></p>	<p>Qualitative methodology</p> <p>Focus groups x 2</p> <p>Semi structured.</p> <p>Video and audio taped</p>	Self-perceived physical limitations and compensatory strategies of living with PD.	<p>Nine participants with PD. 6 men/ 3 women</p> <p>Mean age: 70.6 (range 51-85)</p> <p>mean time since diagnosis: 9.9 years (range 3 to 20 years)</p> <p>H&amp;Y: not given</p> <p>Mobility: all ambulatory either independent/ cane or walker</p>	<p>Sampling: convenience.</p> <p>Setting: community</p> <p>Interview location: local church</p> <p>Geography: USA</p> <p>Culture: not specified</p>	<p>3 themes: variability of experiences among pwPD; variability in compensatory and coping strategies; and the inadequacy of health care system in addressing needs.</p>	Participants not attending exercise group but views on PA undertaking functional activities.
<p>Elsworth, C. Dawes, H. Sackley, C. et al (2009)<sup>42</sup></p>	<p>Qualitative methodology</p> <p>Focus group semi-structured.</p> <p>Notes taken by 3 researchers.</p> <p>Analysis: content analysis</p>	Opinions of individuals with progressive neurological disorders on exercise, barriers and facilitator for PA within community settings	<p>Six participants with PD</p> <p>Mean age: not available for PD</p> <p>focus group alone.</p> <p>Mean time since diagnosis: not given</p> <p>H&amp;Y: not given</p> <p>Mobility: not given.</p>	<p>Sampling: convenience.</p> <p>Setting: community</p> <p>Geography: UK</p> <p>Interview location: conference room University</p> <p>Geography: UK, Oxfordshire</p> <p>Culture: not specified</p>	<p>PD: barriers</p> <p>Difficulty moving about in public spaces. Medication affects timing of exercise sessions and coordination and consideration is needed at to when in should be taken. Pool temperature too cold. Losing balance</p>	Study included participants with a variety of neurological conditions. However only analysis of PD information reviewed. As none of the findings were supported by an illustration no data was able to be extracted for further synthesis.

Erikson, BM. Arne, M. Ahlgren, C (2013) <sup>44</sup>	Constructivist Paradigm  Grounded theory methodology  One to one semi- structured interview Audio taped and transcribed	Meaning of physical exercise in pwPD	11 participants with PD who were active in exercise programs for >1 year 6 men /5 women. Median age 75 years (range 61-81) Median years since diagnosis 8 years (range 2-17) H&Y: ranged from 1- 4 Mobility: independent with / with aid H&Y Stages 1-2 participated in aerobic exercise class. Stages 3-4 participated in Circuit exercise class	Sampling: Purposive (gender, years since diagnosis, grade of impairment) Setting: community Interview location: participants home/ physio department/ public place dependent on choice. Geography: Sweden Culture: not specified	One core category “keep moving to retain the health self” Six categories: “Having explicit life goals” & “Having confidence in one’s ability” (adherence to PA) Taking rational position” (starting point for exercise habits) “Exercise to slow progression” “Exercise to achieve wellbeing” “Using exercise as a coping strategy” (factors for PA adherence)	Clear methodology with a theory produced from the data. Participant voice represented through quotes but examples of codes / illustrations quite concise. Three findings did not have an illustration and were therefore not included in the data extraction and subsequent analysis
Hammarlund, CS. Anderson K. Anderson, M. et al (2014) <sup>48</sup>	Qualitative methodology Method: Semi- structured interviews Recorded and transcribed Analysis: systematic text condensation	Significance of walking	Eleven participants with PD 7 men/ 4 women Median age:71 Median years since diagnosis: 7 years H&Y: stages 2-5 Mobility: walking but balance impairments and 4 used walking aids	Sampling: purposive (PD severity, gender, age) Setting: Community setting Interview location; home Geography: Sweden Culture: not specified	5 categories: Changed walking ability, Emotional reactions, Strategies to manage the impact of walking difficulties, Social consequences, and Independence and integrity. The ability to walk has a complex and multifaceted impact, including physical and emotional aspects, as well as independence and to participate in society.	Data analysis well described. Participant voice strongly represented with illustrations for each theme/ category.

					Impaired gait afflicts internal and external representation and a negative psychological impact on self-concept and coping abilities. The sense of being able to walk without help appears to be intimately linked to an individual social identity and emotional wellbeing, integrity and presumably QoL	
Hislop, J. Gray, S. Melling, S. et al (2015) <sup>53</sup>	Mixed methods  Focus group Analysis: thematic	Barriers and facilitators to PA and the experience of attending a long term exercise group	Eight participants with PD (4 males/4 females) Mean age: 71 years Minimum time since diagnosis 6 years. H&Y: not stated	Sampling: convenience Setting: not stated Interview location: not stated. Geography: UK Culture: not specified	Four key themes: Benefits of attending the group; The group as a motivator; Factors contributing to long-term success of the group included social support, fun, ownership of and accountability to the group; Barriers were identified as transport difficulties and the psychological effect of seeing people with more advanced PD	Search results identified abstract from poster presentation. Author contacted but no reply. Subsequently research summary of study found published on author's university website. Only one finding was supported by participant voice and subsequently extracted for analysis
Houston, S. McGill A. Lee, R. et al (2015) <sup>47</sup>	Mixed methods Semi structured one to one Interviews / focus groups / diaries /observation  Thematic analysis	Perceptions and experiences of pwPD dancing and value of dance program (ballet)	53 participants Mix of male and female Majority of Age range 60-80 Mean time since diagnosis: not given H&Y stage not stated Mobility: independent	Sampling: convenience Setting: community Focus group: at dance center Geography: UK Culture: not specified	Themes; fluidity of movement; balance and stability; posture; improved sense of physical health; cognitive functioning; aid to daily life. Motivation to keep coming: inclusion and community, group motivation and bonding; expression; quality; uniqueness; intellectual	Two studies published on the same group of participants. The 2013 study described the methodology in detail but participant voice was limited. Data were extracted from the 2015 study 2, which was the final report on the 3-year mixed methods study. The English

					<p>and physical challenge; feeling good and feeling capable; dance education; music.</p> <p><b>Certainty about the future:</b> make some positive changes in your life and manage your situation so you can continue to do things you enjoy; have hope for the future; enjoy new things; sense of achievement; develop more confidence; have fun and make friends; develop a community with others with PD.</p> <p>Interference of symptoms on everyday life:</p> <p>Freedom:</p> <p>Social participation:</p> <p>Conclusion</p> <p>Dance program offers an activity and cultural experience, which is multifaceted. Participants engage for many reasons and find great significance in attending regularly. Dancing helps pwPD to nurture an active lifestyle not just physical but also the psychological, emotional and social side</p>	<p>National Ballet Dance for Parkinson's program lasted for 12 weeks. Qualitative data was gathered through multiple interviews, focus groups and participant observation. Only the qualitative data from participants with supporting illustrations were extracted and subsequently analyzed.</p>
Jones, D. Rochester, L. Birleson, A. et al	Qualitative study (part of mixed methods) Semi-structured	Personal experience of everyday walking,	Twenty participants with PD (12 male/ 8 female) Mean age: 65	Sampling: Convenience Setting: unclear Interview	Key theme: walking 'plus' was made up of 3 components. Walking whilst doing something	Part of mixed methods study. Focus was on walking but study included as walking is a PA activity.

(2008) <sup>50</sup>	interviews. Supplemented by field notes Recorded and transcribed  Analysis: NUD*IST N6 software	challenges and strategies to compensate for difficulties	(range 50-80) Mean years since diagnosis 10 (range 2.5-26) H&Y: mild to moderate. Mobility: independent	location: participants home Geography: UK Newcastle Culture: not specified	else; walking in different environments; walking after another activity. Two key strategies for addressing challenges: monitoring walking using concentration; correcting walking through generating rhythm and size of steps.	Carers were present during interview but only findings from pwPD were extracted and synthesized for the analysis. Limited participant voice for some findings. Findings related to carer support were not extracted.
Khalil, H. Busse, M. Quin, L et al (2017) <sup>61</sup>	Mixed methods Interviews  Analysis: thematic	Focus was to explore feasibility of intervention - Intervention group completed 8 weeks of home based exercise and walking program.	Sixteen participants with PD Intervention group (12 male /4 female) Mean age 58.4 (SD 13.5) Time since diagnosis 8.9 years (SD 6.4) H&Y 2.4 (SD 0.72)	Sampling: Convenience. Setting: community Interview location: not specified Geography: Jordan Culture: – mono culture Arabic	Themes: Enablers; Personal challenges; cultural challenges	Pilot study. Focus was on cultural barriers and motivators to the exercise program. Limited information re qualitative methodology. Illustrative quote given for every theme
Khalil, H. Nazzal, M. Al-Sheyab, N. (2016) <sup>57</sup>	Qualitative Focus groups (n=6) (separate genders) One to one interviews (n=7) Supplemented by field notes  Recorded and transcribed  Analysis: thematic	Focus on perceived barriers and motivators for exercise participation	Thirteen participants with PD (7 male/ 6 female) Mean age: 54.9 (range 38-71) H&Y: ranged 1 to 4 Time since diagnosis: not stated	Sampling: convenience and stratified (gender) Setting: community Interview location: research center Geography: Country Jordan Culture: mono culture Arabic	Key theme; lack of previous participation in any disease specific exercises; Barriers: difficulty of diagnosis; lack of information support; lack of referral to PT; disease specific issues; and setting related issues. Motivators: Outcome expectations; family support.	Limited detail re qualitative methodology as to why use of focus groups and interviews. Data from Interviews with neurologist was not extracted. Findings were supported by illustrative quotes from pwPD
Kunkel, D. Robinson, J.	Qual aspect of mixed methods	Appropriateness of dance as an	7 men (age range 65-79)	Sampling: Purposive	Dance is appropriate and acceptable to PwPD and	Search strategy identified conference abstract and

Fitton, C et al (2017) <sup>54</sup>	Semi structured Interviews (within one month of completing dance class)  Thematic analysis	intervention for PwPD. (experiences and view about: the venue / access issues; instructors teaching styles; challenges encountered; perceived impact on mobility and other outcomes; interest in continuing with dance	7 women (age range 49-81) Time with illness: 1-14 years. H&Y stage: 1-3	(maximum variation – age/gender and relationship with dance partner) Geography UK Setting: community dance class Interview location: participant's home. Culture: not specified	inform plans for running the dance program on a larger scale for RCT Views on experience on being partnered with their spouse or a volunteer/ managing potential sources of tension or difficulty/ views on the experience of being a dance partner/ views on continuing with dance classes	author contacted for more detail. This resulted in the inclusion of this published paper from one of the authors. Study included data from dance partners but only data extracted with from pwPD
O'Brien, C. Clemson, L. Caning CG. (2016) <sup>45</sup>	Interpretivist Constructivist Paradigm Grounded theory methodology. One to one semi-structured interviews Recorded and transcribed Grounded theory – theoretical model provided	Focus: meaning of exercise and how other factors interact and influence exercise behavior of individuals with PD	Subset of individuals with PD who had been enrolled in the 6/12 exercise arm of a falls prevention trial. Eight participants (6 male/ 2 female) 2 participants completed exercise program and 6 did not. Age >40 years old H&Y either 2 or 3 Time since diagnosis: range 3 to 11 years	Sampling: Convenience. Setting: community Location of interview: patient's homes. Geography: Australia Culture: not specified	4 main themes: adapting to change and loss, the influence of others, making sense of the exercise experience, and hope for a more active future 3 new influences on exercise participation: non-motor impairments of apathy and fatigue, the belief in a finite energy quota, and the importance of feedback	Search strategy identified a published PhD thesis, a poster presentation and a published research article, which was included in the thesis. Poster presentation not included as not enough detail. To prevent duplication, data from the published research article was only used Exercise program was completed unsupervised at home 3 x a week and supervised 1 x month and last 6 months. All findings were supported by illustrations
O'Brien, M. Dodd, KJ. Bilney, B (2008) <sup>46</sup>	Phenomenological theoretical framework and a grounded theory	Focus: positive and negative aspects and outcomes of a	Twelve out of 13 participants with PD (2 female and 10 men) who	Sampling: Convenience Setting: community	4 themes: Motivators for participation in PRST were broader than physical outcomes; the outcomes	PRST program well described. Study undertaken in conjunction with quantitative review of



	methodology Semi –structured: One to one interviews	community based progressive resistance strengthening program (PRST), motivators to begin and continue, barriers to participate and or complete	participated in a 10- week community based PRST program participated in interviews. Mean Age: 67.8 (range 50-76) Time since diagnosis Months: range 2- 192 H&Y stages 1-4 (though this included all participants – not just the 12 who were interviewed) Mobility: mobile	Location of interview: not stated Geography: Australia Culture: – not specified	were broader than just physical outcomes; the indicator of success for participants varied and the participants' experience of a disease specific exercise program was positive	PRST program. Study identified and described theoretical framework and methodology. All themes were supported by participant voice – though some findings were better supported with illustrations than others.
Pretzer- Aboff, I. Galik, E. Resnick B. (2009) <sup>51</sup>	Grounded Theory:  One to one semi- structured interviews (with exception of a couple interviewed together).  Content analysis	Focus: facilitators and barriers that pwPD encounter in trying to optimize participation in functional activities and exercise.	Three people diagnosed with PD (2 male and 1 female) and 7 caregivers. Data analyzed together. Mean age: unable to obtain data Time since diagnosis: unable to obtain data H&Y	Sampling: purposive selected (PD and carers) Setting: community. Interview location: quiet, private place. Geography : USA Culture: not specified	5 themes: Personality components, Physiological symptoms, Communication difficulties; Environmental factors, Tricks of the trade to optimize function	Participants and caregivers interviewed together. Only information from pwPD with illustrative quotes were extracted and synthesized – themes 1-4. Clear section, which described the process for credibility and confirmability of qualitative date.
Quinn, L. Busse, M. Khalil H. et al (2010) <sup>56</sup>	Qualitative Design One to one semi- structured interview Recorded and transcribed. Analysis: grounded theory.	Focus: attitudes and experiences of early to mid PD in participating in independent exercise programs, identification of barriers.	Part of study on pwPD and Huntington's disease. Data from PwPD (n- =5) 1 female/ 4 male. Data analyzed together but able to determine PD specific quotes	Sampling; purposive early to mid-stage PD from research database. Setting: community Interview location: patient's homes.	2 main themes: Barriers to engaging in self-directed home exercise: disease specific limitations/ safety/ location of exercise Theme 2: strategies for motivation: setting targets and having knowledge of benefits of exercise/ internal motivation	Only data from pwPD, which was supported by illustrative quotes, was extracted and synthesized

			H&Y early to mid-stage. Time since onset symptoms: range 1-9 years Age range: 50- 60 Mobility: independent without aids.	Geography: UK Culture: not specified		
Ramasamy, B. (2015) <sup>41</sup>	Qualitative study: Participatory action research Focus groups Thematic analysis	Focus to investigate exercise class participant motives for engaging and continuing participation in exercise classes	Numbers and stages of PD not given	Sampling: included people with PD and their spouses, 3 exercise groups (aqua-aerobic, circuits and posture group) Setting: community Interview setting: not stated. Geography: UK Cultural: not specified	4 themes identified: Communication: was a hit and miss issue, and sometimes needs to be better/consistent. Education: Saw elements of both people learning and teaching one another Personalities: the humor/optimism /inspiration from the group members, the atmosphere of support, from class leaders and their characteristics came out as important. Other support: social elements, shared experience and committee back up.	Search strategy identified poster presentation. Author contacted and provided research thesis. The focus group identified 4 themes but did not provide illustrations to support the participant voice. Therefore no findings were extracted
Ravaneck, MJ. Schneider MA. (2009) <sup>30</sup> ,	Qualitative study: Phenomenology One to one semi-structured interviews and field notes. Thematic analysis	Focus: how social support influences PA participation as perceived by pwPD ( early stages) How perceived support interacts with	7 people with PD (3 female and 4 men) Mean age 52.1 (SD 4.9) Mean PD duration 42 months (SD 25.7) H&Y: stage 2 All were physically active.	Sampling: Purposive – stage 2 (aged 45-60) Setting: community. Interview location: research center Geography:	ICF model – environment factors (built and natural environment, products and technology, ecotone issues, and accessibility knowledge and social support. 3 main types of support (instrumental, emotion, informational) had a	Only study that specifically addressed social support for physical activity. All findings included as supported by illustrations

		perception of control to influence this participation		Canada Cultural: not specified	positive impact on PA participation. PA participation used as a means to help control progression of PD	
Sheehy, TL. (2014) <sup>49</sup>	Semi-structured interviews face to face (2 interviewers) audio-transcribed. Follow up interview: 3 months later via phone (n=17) or at the program's gym (n=2) for member checking / follow up questions post analysis (data dealt with as previous and included into analysis) Analysis: IPA NVivo to store and organize data	Focus: experience of social relationships, physical self-perceptions and posttraumatic growth within group PA	20 people (8 males/ 12 females) currently or previous participants non-contact boxing program for pwPD (attendance average 4.15 year (SD 2.06) Mean age 85.6 (SD 6.47) Caucasians Most had a postsecondary degree or diploma (n=17) Time sign diagnosis = 8.75 (SD =7.94) H&Y: not stated	Sampling: Purposive (inclusion criteria – English speaking participants in boxing program) Setting: community Interview location: programs gym; public library; university conference room. Geography: USA Cultural: mono culture (Caucasian)	Themes – 5 categories: physical ability of participants, psychological challenges faced by participants in the program, social comparisons made by participants to other members; social support between members and trainer, and psychological outcomes from being in the program.	Published Masters thesis. Strong emphasis on positionality and theoretical framework. Good description of program. All main themes used as all were supported by illustrative quotes.
Westheimer, O. Mcrae, C Henchcliffe, C et al (2015) <sup>55</sup>	Mixed methods design. Quantitative measures and face-to-face semi-structured interviews. Audio recorded-coding and categorization Thematic analysis	Focus: participants experiences of dance class on QoL, adherence, and value of class	12 people (6 male/ 6 female) Mean age 66.2 (SD= 7.3) H&Y = 1-4	Sampling: Convenience /snowball sampling. Recruited by neurologist and other patients. Inclusion criteria = aged over 30, diagnosis of PD. Mobile with or without	Interviews suggested that the value was not limited to physical functioning. Benefits related to QoL, and wellbeing that were not reflected in changes on quantitative measures. Supportive emotional and social experience along with PA appear to have kept attendance strong.	Participants classified into 'worse' or 'better' based on changes to objective measures rather than themes. Very difficult to extract qualitative data as this was poorly presented with little information with regards to coding of themes. Two findings were extracted, and a supporting illustration was

				<p>assistance, give informed consent and medical clearance.</p> <p>Attended dance class 16 session (8 weeks :20hrs)</p> <p>Geography: USA Multicultural (white/ African American/ Hispanic/ Other)</p>		<p>extracted from the answers to the interview questions presented in table 4 and table 5.</p>
<p>Legend: H&amp;Y, Hoehn and Yahr disease classification, QoL Quality of life, IPA Interpretative phenomenological analysis, pwPD, People with Parkinson's disease, PD, Parkinson's disease, PA, physical activity, ICF, International classification of functioning, disability and health, PT, physiotherapist, RCT, randomized controlled trial,</p>						

1 **Appendix V: List of study findings and illustrations**  
2

Article Reference:	<b>Bassett, S. Stewart, J. Giddings, L. (2012) Nordic walking versus ordinary walking for people with Parkinson's disease: A single case design<sup>52</sup></b>
Finding	Experience of the Nordic Walking program: The progressive manner in which the walking phases were implemented gave the participant confidence with her walking: [U]
Illustration	"Starting on flat surfaces first, that are not near road traffic - like at the park and university grounds, meant / could concentrate on Nordic walking; I didn't need to think about where I was going... That helped with my confidence so that I was not distracted by all the road noises and people going past. After six weeks, I became less conscious of the poles; I did not need to think all the time about how to walk with them. The poles became an extension of my arms. Once I had mastered all of what is involved, I found I was self-correcting and walking quite confidently" participant p120 [U]
Finding	Experience of the Nordic Walking program: Walking with a designated person enhanced commitment [U]
Illustration	"I think having a commitment to meet someone at a specific planned time was most important. Let's face it; what I really felt like doing some mornings was to stay in bed! It would have been easy to make excuses to myself if I did not know I had to meet you." Participant pg 120 [U]
Finding	General health: Participant noted that over the Nordic walking phase, changes occurred in her general wellbeing especially with her appetite, sleep and energy levels. [U]
Illustration	"After a couple of weeks of Nordic walking I actually felt hungry again !... I hadn't realized that I had not felt that for a while. I had been worried about having to use sedatives to sleep. A few weeks into the program... I cut my dose and found I was able to get back to sleep after waking in the night." participant p120 [U]
Finding	Physical and psychological wellbeing: When using the poles the participant found she could overcome some of her physical and psychological limitations [U]
Illustration	"The poles opened up my world again. I am not so overwhelmed on social occasions. I used to hesitate going where I knew there was going to be a crowd - especially if there was a possibility that there would not be seats provided. Now I just take my poles and use them as supports and that helps." Participant pg 120 [U]
	<b>Bognar, S., Defaria, AM. O'Dywer, C et al (2017) More than just dancing: experiences of people with Parkinson's disease in a therapeutic dance program.<sup>59</sup></b>
Finding	Connecting through dance: the need for socialization was articulated as a central motivator for attending class, as participants admitted that living with PD could be isolating. [U]
Illustration	"When you get a Parkinson's diagnosis, [you] tend to back into a cage somewhere where nobody can see my weaknesses. You tend to exclude yourself from society. When you join something like Dancing with Parkinson's you become part of a larger group and it's much easier to fight that weakness... . The other classmates are a benefit that I didn't expect or think about at the time". [P9] pg 3 [U]
Finding	Redefining the self: seeking knowledge to become proficient in self-management [U]
Illustration	"Going to class you're not giving in – you're getting back. You're getting something to help yourself." [P2] pg 4 [U]

Finding	Dance and the mind: Participants reported that the class provided opportunities to coordinate their body in new ways and promoted use of different areas of the brain. [U]
Illustration	"[The brain] gets exercise at Dancing with Parkinson's because most dances are more than one step... when they give me the second thing to do at the same time... I notice it immediately." [P9] pg4 [U]
Finding	Dance and the body: participants reported a desire to maintain their current functional status and to slow physical deterioration as motivation for continued participation [C]
Illustration	"It has led to some fluidity, which might not have been there in the body earlier." [P1] pg4 [C]
Finding	The emotional experience: participants agreed that attending the dance class improved their mood. [U]
Illustration	". .you grab a partner and go around, and she smiles, but can't speak and she's happy. Emotionally it affects me as well because it's my benefit to make her happy." [P8] pg4 [U]
	<b>Crizzle, AM., Newhouse, IJ. (2012) Themes associated with exercise adherence in persons with Parkinson's disease: A qualitative study<sup>5</sup></b>
Finding	Reassurance from instructor: was an important motivator of exercise adherence. [U]
Illustration	P4 "A few people started off better than me... and that bothered me. But the instructor told me not to worry about it and that I should work at my own pace. I didn't think I could do it. I nearly gave up. But the leader always insisted that I could do it, so I had to prove myself and then I could."pg180 [U]
Finding	Group structure and group support: participants reported developing a good rapport with each other over time and were encouraged by the improvements made in their physical and social abilities. [C]
Illustration	Participant 1 said (pointing to participant 4): "He actually talked to me later on, at the beginning he just sat there completely mum"pg180 [C]
Finding	Improved psychological wellbeing from perceived physical benefits: Participants noted improvement in their normal everyday activities. [U]
Illustration	Participant 1 "I find it so much easier to reach for items in shelves that I had difficulty getting to before. I can also cut my meat and vegetables better. I feel like I can put more pressure on the knife. Such little things, but these play a big part of my daily living. I can't believe these things can be improved just by exercising." P1 pg180 [U]
	<b>Davis, JT. Erbart, A. Trcinski, BH et al (2003) Variability of experiences for individuals living with Parkinson disease.<sup>58</sup></b>
Finding	Physical limitations and compensatory strategies: participants shared similar physical limitation related to PD, however, the way in which these limitations affected each participant was unique. [U]
Illustration	"With this disease you have similarities; you know they are just similar and at other times it's like your disease is custom made to you." Participant pg 40 [U]
Finding	Falls: Issues pertaining to falls included their unique experience of falling, how falls have impacted their life and measure they have taken to prevent future falls. [U]
Illustration	"I think balance is probably for me the worst thing... I've had one fall, but I'll remember that 'til they bury me, that sudden realization of what happened.

	Fortunately , I was in my bedroom and fell on the nice carpeted floor, but it was a hell of a sensation.” participant pg 40 [U]
Finding	Walking: Participants identified 4 specific symptoms that affected their ability to walk; difficulty initiating movement, shuffling, festinating gait and freezing. [U]
Illustration	“It affects the first step I take, the second and third steps are a lot easier than the first step. So if get pointed in the right direction, and I get moving , I can continue moving but that first step can be a real challenge sometimes.”pg40 [U]
Finding	Functional mobility: Participants identified additional areas that were problematic; decreased mobility in bed; transfers from sit to stand as well as solutions. [U]
Illustration	“Moving around in bed is almost an impossibility. There seems to be so much resistance between the sheets and it just seems impossible.” participant pg40 [U]
Finding	Medication cycles were recognized as a leading contributor to participants’ physical limitations. [U]
Illustration	“I notice my problems walking are dependent on my medication ... I skip my medication , my balance gets bad, I lose my stride, and feel very uncomfortable walking.” P pg41 [U]
Finding	Altering performance of activity of daily living: participants managed ADLs by altering how they were achieved including; increased time and being organized [C]
Illustration	“Some participants acknowledged organizing and taking advantage of the productive time when their medication was ‘on’. Example of preparation were writing out checks before going to the store and organizing commonly used areas into workstations that were equipped with frequently needed items.” (author page 41) [C]
Finding	Participants identified coping with the disease through maintaining a positive outlook. [U]
Illustration	“Every once in a while I think, ‘hey , I’m lucky I have Parkinson’s’, I have friends who have had lung problems , who have had heart attacks, total loss of vision and are buried. We are alive.” P pg41 [U]
Finding	Participants coped with the disease by attempting to maintain a sense of normalcy. [C]
Illustration	“One participant explained how she hid her foot, which showed dyskinesia, under the desk, to prevent co-workers from discovering that she had PD.” (author pg 41) [C]
Finding	Being a self-advocate was a method of dealing with the disease. [U]
illustration	“Unless you are lucky enough to have a nurse practitioner like - --- or you find a good physical therapist, you have to be an advocate, you have to say ‘I want physical therapy, what can you write me a prescription for? I want to go and be evaluated about how to use a car or I want to learn about how to get my oxygen better’ ... so I feel that you have to gather information, you have to be an advocate and tell them what you want and hope that you have a good circle of family and friends”. Pg 42 [U]
Finding	Health Care issues: the current health care system does not meet the comprehensive needs of individuals with PD. [U]
illustration	“it’s kind of pitiful that we don’t have outreach with physical therapy, we have no national , state or local outreach programs, look at the table of us, how much we would improve if we had one hour of outreach a week.” pg42 [U]
	<b>Erikson, BM. Arne, M. Ahlgren, C (2013) Keep moving to retain the healthy self: the meaning of physical exercise in individuals with Parkinson's disease.<sup>44</sup></b>
Finding	Being Part of life: participants expressed an aim to continue to participate in valuable

	areas of life even if support was needed for managing to do so. [C]
Illustration	"When you aren't disabled... you think that it's the practical things which are... the main thing, but it isn't. It's how you feel inside... and then... then it's not such a big defeat if you can't get your shoes on. What I mean with being part of life, it's probably to be needed." [C]
Finding	Trusting own experiences: meant being attentive to the signals from one's body, and acting in the best way according to one's knowledge, beliefs and experiences. [C]
Illustration	"... I keep myself a bit busy at home... I have recorded a lot of tunes ... and do certain exercise there... and so on. So ... I rarely sit still... if I put it that way." Participant pg 2240 [C]
Finding	Identifying oneself as physically active: related to the participant definition of themselves as a physical active person both in the past and in the present [U]
Illustration	"...one was out running and doing aerobics and ... such things. I used to participate in those gymnastic displays we had at that time... and that was fun... of course that was a driving force... () and there the habit too ... (to exercise)." participant pg 2240 [U]
Finding	Taking responsibility for own health: generated from the decision making that preceded start to exercise and included the decision to believe in the good effect of exercise and the counteracting effective of a passive lifestyle [C]
Illustration	".. and then its only making the best of the situation... one mustn't think negatively, one has to try to avoid that... think positively, try turning everything into the best instead." Participant pg 2241 [C]
Finding	Have to keep on moving: was a driving force for exercise, emanating from sustaining self-image, believing in the benefits of keeping oneself active was the underlying construct [U]
Illustration	"And... then it's my goal to try to keep myself ...keep myself on the go as long as possible so that I ... yes, to be part of life. Not only to sit on a park-bench and ...hear somebody talk ... but ... to be active as well as I can..." participant pg 2241 [U]
Finding	One should see to one's health: a knowledge-driven obligation towards oneself and toward supportive significant others and health professional, that exercise is necessary to good health. [U]
Illustration	"One tried to do (exercise) as well as one can in everything and ... doesn't try to waste time in any way but tries to do as well as possible. ... because the doctor said that ... exercise is very important for everybody ... for everybody who has Parkinson's disease... so I mustn't become an idler so ...out and ...yes walk a lot with poles to keep up the agility in arms and shoulders." Participant pg 2241 [U]
Finding	Experience wellbeing through accomplishing: focused on an aspect of wellbeing that derived from the satisfaction of the achievements in itself [U]
Illustration	"... the body feels good, he say "oh, it's so good that you've done this" and so on and ... it's difficult to say what it is but... I think I feel very good when I've achieved something." Participant pf 2242 [U]
Finding	Having feelings of coherence: The achievement of attending an exercise program and having support by the regularity and the promoting of the program were important facilitating factors for those participants. [U]



Illustration	"I think it's very good with that hour that... at least once a week gets... the muscles there and there ... and do something. ... I feel satisfaction by being able to participate... that is the primary thing, I think. And ... also to feel that the body manages, because... I sometimes think when we're exercising, that we are incredibly capable considering our capacity. And sometimes you're not capable at all, but ... then when you experience that "Oh god , I can do this" then you get a kick..." participant pg 2242 [U]
	<b>Hammarlund, CS. Anderson K. Anderson, M. et al (2014) The significance of walking from the perspective of people with Parkinson's disease.<sup>48</sup></b>
Finding	Changed walking ability: participants described gait had become slower, they were dragging their feet or steps could be tripping and the feet could get stuck to the ground. [U]
Illustration	"So .... I felt like I sort of walked and dragged a little on ... a little like an old man, sort of dragged my feet." participant pg 659 [U]
Finding	Emotional reactions: Walking difficulties were perceived as aggravating and problematic, causing feelings of sadness and hopelessness. Struggling with activities resulted in frustration and anger. [U]
Illustration	" It's draining your energy and it saddens me. You become angry with yourself when it's hard and things don't work as you want them to. When you do something, things that you've done a hundred times before with ease, take forever to do today." participant pg 659 [U]
Finding	Strategies to manage the impact of walking difficulties: They chose to accept the new situation, to plan their lives in both the long and short term, using cognitive strategies to overcome difficulties.[U]
Illustration	"if I know that I am doing something special then I have to adjust my medication accordingly. And you have to constantly think, think ahead, plan a little more of your activities in relation to the medication and so.... It has clearly changed my life, it really has..." participant pg 659 [U]
Finding	Social consequences: Walking difficulties had an impact on the ability to participate in social activities within or outside the family. [U]
Illustration	"... it changes the whole lifestyle. You don't want to be amongst others. You back away from being in a crowd ... and at various events one feels like an outsider. I simply can't keep up anymore, not like I used to." participant pg 660 [U]
Finding	Independence and Integrity: Participants felt that the ability to walk was important in managing their daily activities and work and was central to participation in life like everyone else. [U]
Illustration	"Being mobile, to be able to participate in life normally, to be able to move around, take the train, drive the car... to be able to walk to different things without any trouble." Participant pg 660 [U]
	<b>Hislop, J. Gray, S. Melling, S. et al (2015) An exploration of physical activity experiences in people with Parkinson's disease.<sup>53</sup></b>
Finding	Confidence building: Attendance at the group helped build confidence [U]
Illustration	"It gives you more confidence to go out in the world and tackle life. You know, if you've got a wee network of people that understand you..." participant pg 3 [U]
	<b>Houston, S. McGill A. Lee, R. et al (2015) English-National-Ballet-Dance-for-Parkinson's. An Investigative Study 2. A report on a three year mixed methods-research-study.<sup>47</sup></b>

Finding	Fluency of movement: participants have a perception that music helps people to move in a more fluid and coordinated fashion. [U]
Illustration	"The dance made me feel more graceful, moving and flowing with the music, it made me feel that I had to move when the music started." P pg 19 [U]
Finding	Balance and stability: Participants have mentioned an improved sense of body awareness both inside and outside of the dance studio with participants also noting a lack of freezing. [U]
Illustration	"I get a bit of freezing in movement, but I feel I'm less freezing when I come to class. I don't freeze here and when I go back home I don't freeze as often that day." P pg 22 [U]
Finding	Posture: Participants note the challenge in maintaining posture in relation to dance and the difficulties in maintaining posture outside of the class in order to cause permanent change [U]
Illustration	"I think when I go off and I remember to walk so tall, and keep my head up, and swing my arms, just to do movement, and if I think I go dancing and sit up straight, and shoulders back, head up, it's a great image to hold on to." Participant pg 22 [U]
Finding	Progression of Parkinson's: Participants noted that the physical changes may not be as obvious or distinctive as the mental benefits. [U]
Illustration	"It's not just I'm in the mood, but physically I feel different. I don't think about it all the time, but suddenly I realize how much better I feel. More movement, more energy, certainly more energized....I want to stay positive and not think about Parkinson's." Participant pg 24 [U]
Finding	Cognitive Functioning: Participants find the dance classes to be quite difficult with respect to remembering the movement sequences and being able to move different parts of the body simultaneously. [C]
Illustration	"I do think it is good for you. The whole mental activity is on a different plane from physical activity." Participant pg 25 [C]
Finding	Participant expressed what was important to them personally in maintaining a good quality of life [C]
Illustration	"Having confidence to do things / having the ability to keep doing interesting activities /having movement capability and stability / being around loved ones / having a religious belief." Author pg 25 [C]
Finding	Aid to daily life: Participants noted how exercise from class help to alleviate rigidity and pain and improve mobility for everyday activities.[U]
Illustration	"It is typically a matter of identifying the right exercises on each occasion to alleviate the various neuro-muscular afflictions. For my shoulder I noted during the classes that the 'lasso, arrow and sword' provided some temporary relief – so, I used a similar routine at home to improve mobility and it seems to work better than anything else I have tried (e.g. stretching and strengthening)." participant pg 26 [U]
Finding	Motivation to keep coming to the English National Ballet ENB Dance for Parkinson's program were diverse. [U]
Illustration	"I didn't know anyone with Parkinson's before I came to these classes. I was all alone. It's not just about dancing, it's making friends and sharing." P pg 27 [U]

	<b>Jones, D. Rochester, L. Birtleson, A. et al (2008) Everyday walking with Parkinson's disease: understanding personal challenges and strategies.<sup>50</sup></b>
Finding	Walking whilst- walking while doing something else: participants noted that undertaking dual tasks could become challenging. [U]
Illustration	"Sometimes if I concentrate too much on not spilling the tea I sort of forget about going up the stairs ... It's as if my nervous system is overloaded. Can't unscramble the two messages." (P17 pg 9) [U]
Finding	Walking 'in' – walking in different environments: outdoors posed unpredictable challenges and were disliked. Indoors doorways and furniture, the need to constantly change direction and to change positions caused the main challenges. [U]
Illustration	"Having to stop, start and change direction; being jostled; coping with distractions; feeling pressured and self-conscious; and having to concentrate on yourself and others, were all tiring and often frightening." (author pg 10) [U]
Finding	Walking 'after' – walking following another activity: Participants noted an increased difficulty in walking after a activity [C]
Illustration	"Increasingly maneuvering out of dining chairs at a table; rolling to the edge of the bed in order to get the legs over the edge; exiting the bath; turning after standing were reported as challenging, especially in the 'off' state. Initial walking after all these activities was likely to be characterized by shuffling steps, potentially stooped posture, often accompanied by unsteadiness..." (author pg 11) [C]
Finding	Monitoring: walking using concentration: Participants needed to monitor walking quality and consciously correct deficits. [U]
Illustration	"...but I'm always watching, thinking, terrified of falling over but there's that feeling always that you must watch where you are going." (05). Pg12 [U]
Finding	Correcting: Walking through generating rhythm and size of steps. Imagined or actual visual input was used to start and maintain stepping and overcoming freezing. [U]
Illustration	"I had to rehearse mentally if I was going to take a step and then take the step." (20). Pg 13 [U]
	<b>Khalil, H. Nazzal, M. Al-Sheyab, N. (2016) Parkinson's disease in Jordan: Barriers and motivators to exercise.<sup>57</sup></b>
Finding	Difficulty of diagnosis: Participants with PD reported spending a huge chunk of time searching for a basic answer that can justify their symptoms: a diagnosis.[U]
Illustration	"I started to feel symptoms 6 years ago but I have only been diagnosed 2 years later. I was complaining of general slowness of movement and fatigue; simple things would become difficult. The GP excluded PD as it did not fit with my age category, However I doubted it was PD, as the symptoms were similar to my father's, who is also a PD patient. When other symptoms started to appear like tremor, the GP decided to refer me to a specialized neurologist" P5 pg 512 [U]
Finding	Lack of informational support by neurologist: about the importance of exercise or physiotherapy to their condition. [U]
Illustration	"I do not do any specific exercises for managing my condition as I am not aware of any. . . my neurologist has not mentioned this to me." P9 pg 513 [U]
Finding	Lack of referrals to physiotherapy: None of the participants were referred to physiotherapy for explicit management of PD. [U]

Illustration	"Four years ago I was complaining from lumbar disk and for that reason I've been referred to physiotherapy. The treatment was for my back pain but not for the PD." P3 pg 514 [U]
Finding	Disease-specific issues: such as stiffness and fatigue may limit their potential participation in future exercise programs. [C]
Illustration	"All the participants reported experiencing the "wearing off" phenomenon in which these symptoms become much more apparent." Author pg 514 [C]
Finding	Setting-related issues: location of the exercise was considered important for the participants to engage in an exercise program with some preferring home and others hospital [C]
Illustration	"The commitment to the program will be better if it is at the hospital and under the supervision of a therapist. At home, you may get busy with other stuff; defer the exercises and end- up of not doing them." P1 pg 514 [C]
Finding	Outcome expectations: positively affect the participant's decision about getting engaged in a future exercise program [U]
Illustration	"My health is my priority and if exercise would help then I will exercise daily. I really would like to reach that level of doing things by my own and not relying on others; this is all what I want." P4 pg 515 [U]
Finding	Family support: and commitment was perceived as an important element for some participants to initiate and maintain an exercise program. [U]
Illustration	"Family has always been a source of support for me to accept the disease and to deal with it. A lot of mornings I would be very tired sitting on my sofa or lying in my bed until my son comes and asks me to go for a walk with him. His encouragement pulls me up and it's just about the start that is difficult then I get clicked on; I usually feel much better afterwards." P9 pg 515 [U]
	<b>Khalil, H. Busse, M. Quin, L et al (2017) A pilot study of a minimally supervised home exercise and walking program for people with Parkinson's disease in Jordan.<sup>61</sup></b>
Finding	Enablers: Participants reported that DVD was very clear, easy to follow and provided an important tool to continue performing the exercises independently at home [U]
Illustration	"The DVD was simple and easy to follow its use at home was a strong motivator to continue doing the exercises." (table 4 no page no.) [U]
Finding	Perceived improvement: whether in physical or mental status was a key to motivate them to adhere to the exercise program [C]
Illustration	"The exercise program has affected me both mentally and physically before I got to know you and was introduced to this program I used to lock myself away at home fear of falling was a big issue. I was therefore not moving ... Now my mobility has improved dramatically ... I feel as If I have regained big chunk of my life." (table 4) [C]
Finding	Participants report that compensation for transportation helped with adherence [U]
Illustration	"As you know I come from a distance and my participation would have been impossible without covering the transportation costs that was really important aspect." (table 4) [U]
Finding	Continuous monitoring: Participants perceived the importance of initial instructional

	sessions and the weekly phone calls as important elements for initial adoption of the program and also for continuation; they were perceived as important aspects of the program to build self-efficacy [C]
Illustration	"I really prefer doing the exercises at home ... the sessions with therapist were very important to know what I am supposed to do and to build confidence." (table 4 no page no.) [C]
Finding	Social interaction and relation with the therapist: was a strong motivator to adhere to the program. [U]
Illustration	"For the first time ever I felt that someone was truly taking care of me that was the best piece of the intervention. It made me feel in turn that I should take care of myself by committing to the exercise program. The therapist was an excellent motivator." (table 4 no page no.) [U]
Finding	Family support: encouragement provided by family members was perceived to be important. [U]
Illustration	"The family encouragement was very important for me to take this step and start the exercise program with you." (table 4 no page no.) [U]
Finding	Personal challenges: comorbidities such as knee or hip osteoarthritis, cervical or lumbar disk, limited but did not prevent them from engaging in the exercise program. [U]
Illustration	"I have a chronic problem in my knee and some of the balance exercises were causing me more pain ... this did not stop me from doing the exercise ... the therapist helped me in modifying the exercise so that it became more tolerable." (table 4 no page no.) [U]
Finding	Participants perceived that Physical fatigue would limit but not prevent them from engaging in the exercise program. [U]
Illustration	"I lacked the habit of past exercise. This is the first time I have been in a structured program. When I first started, I used to feel tired even after performing only a few movements. This feeling, however, ceased off after few weeks." [U]
Finding	Depression: affected motivation to do anything including getting engaged in the exercise program. [U]
Illustration	"Since I've been diagnosed with PD and I felt low...I became less motivated to do anything in life ... even when you invited me to do the exercises I felt apathetic." (table 4 no page no.) [U]
Finding	Lack of outcome expectations: one participant at early stage believed he was not necessarily in need for exercise as they were still physically fit. [C]
Illustration	"I feel I am physically better than other people... and the nature of my work requires a lot of movements. I work as a plumber; hence I move all the time." (table 4 no page no.) [C]
Finding	Denial of PD diagnosis: participants at early stage were still in doubt of being diagnosed of PD. [U]
Illustration	"I did not do the exercises because I am still not convinced I have PD ... I have this dilemma ... I am really not convinced that I have PD ... next week I will be seeing another neurologist to discuss my case." (table 4 no page no.) [U]
Finding	Cultural challenges: being active is not the norm particularly for old people. [U]

Illustration	"At home I have the fear that my sons will comment on this I am trying to avoid this. I did though all the sessions with the therapist in the clinic but did not do the sessions at home." (table 4 no page no.) [U]
	<b>Kunkel, D. Robinson, J. Fitton, C et al (2017) It takes two: the influence of dance partners on the perceived enjoyment and benefits during participation in partnered ballroom dance classes for people with Parkinson's.<sup>54</sup></b>
Finding	Views on the experience on being partnered with their spouse or volunteer: participants who danced with their spouse or somebody else they knew well, appreciated not only the practical convenience but also the sense of "moral support" and shared enjoyment that this afforded them. [U]
Illustration	Person with Parkinson's: "I wouldn't have liked, I wouldn't have gone if [husband] hadn't have been my partner I don't think. I liked that very much, I liked it a lot." [Brenda: F, age 81, BLOCK 3] [U]
Finding	Managing potential sources of tension or difficulty: It was potentially problematic, both for novice and experienced dancing couples, when a male dancer with Parkinson's found it difficult to fulfil the traditional role that was expected of him. [U]
Illustration	Person with Parkinson's: "She irritated me to the extent that I said "Look I'm supposed to be leading here!" and she said "Yes, but you're not doing it right!" [laughing] Andrew age 73 H&Y3 block 1) pg 5 [U]
Finding	Views on continuing with dance classes: all people with Parkinson's expressed an interest in continuing to dance but none had made firm arrangements to do so. [U]
Illustration	Person with Parkinson's: "I think it, because I can't walk that far, and I can't walk that quickly, certainly regular dancing would take the place of some of the walking that I can't do." Elizabeth: age 71, H&Y2, pg 6 [U]
	<b>O'Brien, C. Clemson, L. Caning CG. (2016) Multiple factors, including non-motor impairments, influence decision making with regard to exercise participation in Parkinson's disease: a qualitative enquiry.<sup>45</sup></b>
Finding	Loss of ability and loss of identity as active self: Participants identified a variety of physical and mental changes attributable to both PD and ageing that caused reduced ability to engage in physical activities and consequently led to adaptations in the way they participated in them. [U]
Illustration	"It's just the limitations of not being able to do things you used to be able to do. You move into a stage where you can't do things that you used to be able to do and I miss very much not having a license to drive a car and so I'm sort of housebound except for my wife, my wife drives me places but it's hard on her too, so it's a hard time." P7 pg 3 [U]
Finding	Focusing on not losing more: adapting to loss of physical ability also involved focusing on what participants could do and trying to prevent further losses. [U]
	"I'm just trying to hold on to what I have. I mean I am quite old. I really felt that I must not overburden the body." P2 pg 4 [U]
Finding	Facing challenges of apathy, fatigue and other health problems were a significant barrier to regular exercise participation. [U]
Illustration	"You've got to battle with willpower all the time." P3 pg 5 [U]
Finding	Relationships with a shared understanding: Participants valued the experience of exercising with others with PD. Having a common purpose and a shared

	understanding were common themes. [U]
Illustration	"It's not that you want sympathy but understanding. So, when you're down there (referring to the group) I actually totally relax because we are all understanding each other." P2 pg6 [U]
Finding	Comparing oneself with others in the exercise group: was another aspect of exercising in a group of people with PD.[U]
Illustration	"That was an incentive for me to put more into it because I could see that one guy in particular was benefitting from it." P6 pg 6 [U]
Finding	Identifying goals: participants had their own individual goals, therefore each participant had different goals and expectations from the program and these were often different from the physiotherapists' goals. [C]
Illustration	"I believe that at my stage of Parkinson's progress that I have to be concerned about power and balance." P6 Pg 6 [C]
Finding	Evaluating if expectations are met: and the outcome of this evaluation was continually changing. [C]
Illustration	"You can get disappointed if you can't do it. P1 The effort really means a lot, but I just sort of glided it through somehow to get it finished ... I didn't do it to my satisfaction." P3 pg 6 [C]
	<b>O'Brien, M. Dodd, KJ. Bilney, B (2008) A qualitative analysis of a progressive resistance exercise program for people with Parkinson's disease.<sup>46</sup></b>
Finding	Motivators for participation were broader than just physical outcomes: they gave a number of reasons for why they chose to take part in the study [C]
Illustration	Participant 1: "[I] was keen to try and assist the program as a participant for the sake of future generations of PD sufferers." Pg 1353 [C]
Finding	The outcomes were broader than just physical outcomes: participants said that there were no significant physical gains, yet they commented favorably about their experiences. [U]
Illustration	Participant 8 said: "I haven't noticed anything physically; maybe just a marginal improvement in the strength of my arms. With regard to my legs, I don't think there has been much change at all, but mentally I think, oh I don't know, I think just being involved with other people sort of, even at this level, helps me a bit." Pg 1354 [U]
Finding	Indicators of success for participants varied: Participants said they used several methods to judge whether they were progressing in the program or not. [U]
Illustration	"I did feel that I was working as I went through the bands, the stronger bands, that, yeah, it did seem to get easier as I went along, particularly with the legs. Much easier." (Participant 12), pg 1354 [U]
Finding	The participants' experience of a disease-specific exercise program was positive: Benefits included sharing information about Parkinson's disease. [U]
Illustration	"[We] exchanged thoughts and notes that we had we all seem to have been on the Internet at various stages, gathering information, and it was very helpful." (Participant 4). Pg 1355 [U]
	<b>Pretzer-Aboff, I. Galik, E. Resnick B. (2009) Parkinson's disease: barriers and facilitators to optimizing function.<sup>51</sup></b>
Finding	Personality components: Participants spoke of personality traits that promoted independence in physical activities such as resilience, determination, need for

	independence, denial of need for assistance, and humor. [U]
Illustration	"I don't ever call for help, really. I try to stay independent." Participant no pg no. [U]
Finding	Physiological symptoms: both motor and non-motor, of PD were noted by people with PD to limit the ability to engage in physical and functional activities. [U]
Illustration	Another participant described his experience with bradykinesia: "It is difficult. I muddle through. . . . It takes me forever . . . my speeds have gone from slow and stop." (no page no.) [U]
Finding	Communication Difficulties: Difficulty writing and speaking because of tremor, hypophonia, and freeze episodes were described as hampering the ability to communicate with others. [U]
Illustration	"I cannot write. There is a stack of condolence letters here, from when my wife died. I initially said I will answer each of them myself. I had all the intentions of doing so, but I couldn't write. So I decided that I could do it all with a machine, on the computer. But I couldn't do it on the computer because I couldn't type either. Now I can't hit the right key for nothing." No pg no. [U]
Finding	Environmental Factors: including the social support network, members of the healthcare team, and the physical environment were identified as either facilitating or challenging the person's day-to-day ability to function [C]
Illustration	"Participants noticed that small spaces, clutter, and stairs decreased mobility." Author no page no. [C]
	<b>Quinn, L. Busse, M. Khalil H. et al (2010) Client and therapist views on exercise programs for early-mid stage Parkinson's disease and Huntington's disease.<sup>56</sup></b>
Finding	Disease specific barriers: Participants with PD, highlighted several factors, namely stiffness, fatigue and problems with maintaining concentration. [U]
Illustration	PD5: "Having the disease does influence my ability to exercise, because I think it is hard to concentrate. So focusing is difficult and also the tiredness and fatigue is another problem." pg 922 [U]
Finding	Lack of information on exercise in PD [U]
Illustration	"I had not any advice as to exercises. We picked up some leaflets at one time in the doctor's surgery, from the PD society, but I don't think there was anything in there that referred to specific exercises or something that was relevant to me." Participant pg 922 [U]
Finding	Barrier: location of exercise Lifestyle issues: Alternatively, some of the clients preferred doing exercises at home rather than going to the gym, because it would fit better with their lifestyle.[U]
Illustration	PD2: "I tend to exercise at home rather than going to the gym because it fits in with my lifestyle really. At the weekend I have my granddaughter and also I am working three times a week." Table III pg 922 [U]
Finding	Benefits of group exercise. [U]
Illustration	PD4: "I think if you want to do the exercise by yourself, it will be very difficult to motivate yourself. If you were in a class which is not necessarily a class of Parkinson's but a class of people in the same fitness range as you and it is organized in a daily or weekly basis, you can along with it. There is the social aspect as well." table III pg 922 [U]
Finding	Setting targets and having knowledge of benefits of exercise: Clients felt that their understanding of the relevance and usefulness of exercises was most critical to



	determining whether or not they participated. [U]
Illustration	PD5: "I think it should be clear how the exercises fit into the program. That's helpful. If I feel that the exercises make a difference, then I can do them more. Also having the general idea of the benefits of doing the exercise. I think the exercise is good for me and by doing the exercise I appreciate that there is a difference." Table III pg923 [U]
Finding	Simplicity of exercise program [U]
Illustration	PD5: "Sessions with physiotherapy actually taking me through with the exercises; that is good I think. They gave me exercises to do at home but I have not continued using them because of a couple of things actually. For back exercises there was no standard to do them. So, you do a lot and a lot of exercises like the hand behind the shoulder or the hand in front but actually you do not know what for the exercises are and the differences are tricky . . . . I think exercises should be simple and clear how they fit into the program. That's helpful." Table III p923 [U]
	<b>Ravanek, MJ. Schneider MA. (2009) Social support for physical activity and perceptions of control in early Parkinson's disease.<sup>30</sup>,</b>
Finding	Sources of support: Family members - the most salient forms of support provided by participants' families were instrumental and emotional support. [U]
Illustration	"They encourage me, goad me, embarrass me into doing some [activities] and they also will alter their activities to accommodate me which is very good. [My husband] just you know, like he always is trying to get me into doing more. He probably encourages me and gets me going more than I would do myself." Pg 1929 [U]
Finding	Sources of support: Friends - The main forms of instrumental support were the provision of transportation and mutual participation in physical activity. [U]
Illustration	"They'll come out and walk with me sometimes or friends will come out and bike with me . . . it's nice to have friends who are compassionate, and ah understand what you are going through." Participant pg 1930 [U]
Finding	Sources of support: People in the workplace - This type of support commonly took the form of organizing work schedules to allow for time to participate in specific exercise programs. [U]
Illustration	"They were all very supportive because I started [exercising at the research center] when I was still working. So, they all made sure, no matter who was working with me, that I got off in time." P pg 1930 [U]
Finding	Physicians: participants' reports on GPs and neurologists was the lack of support provided with regards to physical activity participation. [U]
Illustration	"[My] GP really didn't say much. Actually, neither doctor really encouraged [physical activity]. They didn't discourage it, but they didn't really come out and say, 'You should join this,' or 'You should do that.' There's probably a little bit more work that could be done there to keep people active." Participant pg 1931 [U]
Finding	Social support groups: An important factor contributing to the perceived suitability of these groups for participants was the variability in disease progression of group members. When participants were not able to relate to other group members, the support groups were seen as negative and this led to attrition. When participants were able to relate to other group members, these groups offered a tremendous amount of support. [U]
Illustration	"I went a couple times [to a support group] but they're all, I hate to say it, quite elderly

	and that for me personally is very depressing . . . They're all a lot worse because they've had it longer so they're very few young people . . . So, we went to the social group but it's like being at a senior's centre . . . so I haven't gone after. . . . It is really depressing to see what you have to look forward to becoming." Participant Pg 1932 [U]
Finding	Perceptions of control: participants viewed physical activity as a means to slow the progression of the disease, and help maintain their independence [U]
Illustration	"I have no other answers with this, with this disease . . . it's something I want to try and fight . . . and I don't know how to fight it [pause]. I don't want to be overmedicated. I'm hoping exercise can flatline it or slow down the progression or help me. I don't know. So, it's mainly my decision to [participate in physical activity]." Participant pg 1933 [U]
	<b>Sheehy, TL. (2014) The Parkinson's experience of group physical activity- Understanding social support, social comparison, physical self-perceptions, and post-traumatic growth.<sup>49</sup></b>
Finding	Physical ability: participants identified improvements in physical competence post program [C]
Illustration	"I wanted to do everything I could to delay, I think, keep active and delay if, if possible any progression." (Fiona) participant page 32 [C]
Finding	Psychological challenges: participants feared doing a program which was unfamiliar and where they may hurt themselves [U]
Illustration	"I had all those kind of fears. Well, you know, what if it's like one of those classes you go into and the person at the front is saying, no pain, no gain, and you hurt yourself and then you can't do anything." (Imelda) pg 32 [U]
Finding	Social comparison: made with others varied based on disease and ability and resulted in both positive and negative emotions [U]
Illustration	"When you talk to other people then, that have been doin' this, like, [Marty] for thirteen years and she's in my class and they're doin' better than me, much better than me...I think, we'll see, you know, there's a good possibility that thirteen years from now I might be where I am." (Belle) pg 33 [U]
Finding	Social support: centered around the varied types of support given and received by participants [C]
Illustration	"I just kinda take it upon my, you know, if I see somebody not doin' what they, you know, need to be doin' or goin' in the wrong direction, I, I just feel like I should help." (Albert) pg34 [C]
Finding	Psychological outcomes: being in the program and improving physical competence allowed participants to express surprise at their ability and a newfound confidence and realization that they have new possibilities. [U]
Illustration	"It just gives you an all over good feeling that you can, you can do it and, uh, I would never have thought, before I had the Parkinson's, that I could do anything like this." (Silvia) pg 35. [U]
	<b>Westheimer, O. Mcrae, C Henchcliffe, C et al (2015) Dance for PD: a preliminary investigation of effects on motor function and quality of life among persons with Parkinson's disease (PD).<sup>55</sup></b>
Finding	Physical social and emotional benefits of the group [C]

Illustration	"Very positive communal experience; pleased to see improvements in others." participant pg1266 [C]
Finding	The participants reported benefits related to QOL and wellbeing that were not reflected in changes on quantitative measures. [C]
Illustration	"Less helpless; doing something to help myself" [C]

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